VOL. 3 NO. 3 1980

DISABLEDUSA

Theatre and Disability . . . Broadway Plays:
Elephant Man; Whose Life Is It Anyway? . . .
Plus interviews with Bernard Bragg and Philip Anglim . . .
and much more

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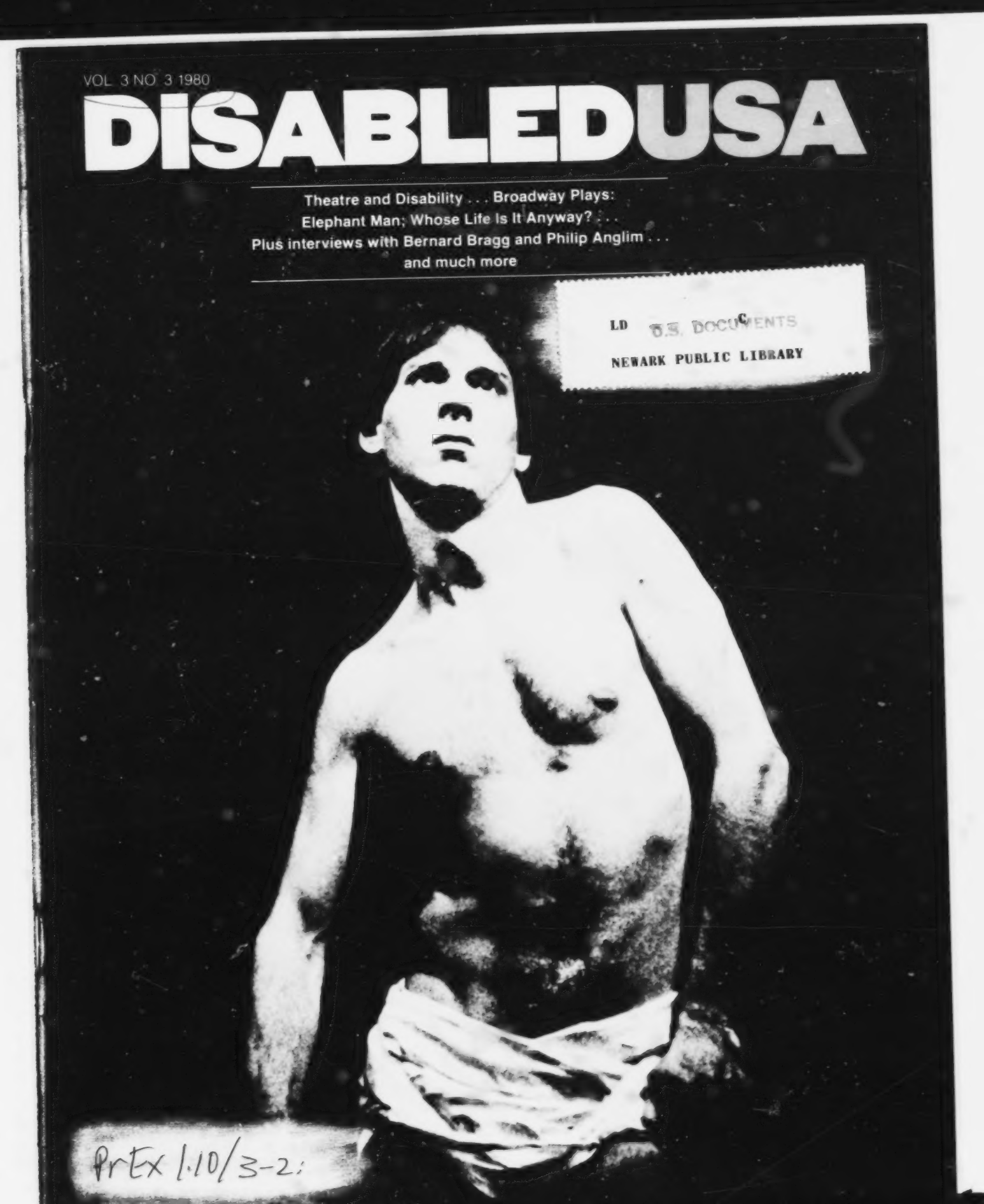

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DISABLEDUSA

VOL. 3 NO. 3 1980

Disabled people are now being presented as the focus of many stage productions. In reviewing these efforts, it is important to remember that disabled characters are still, for the most part, portrayed by able-bodied actors—the "Great White Way" is still a bumpy road for talented, disabled actors.

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DISABLED USA reports progress in opportunities for all handicapped workers, keeps Governors' and Community Committees informed of new ideas and activities, and provides all readers with general information concerning developments in rehabilitation and placement of people with disabilities. In a phrase, Disabled USA presents the case for disabled adults.

The Chairman of the President's Committee on Employment of the Handicapped has determined that the publication of this periodical is necessary in the transaction of the public business required by law of this Agency. Use of funds for printing this periodical has been approved by the Director of the Office of Management and Budget through August 15, 1981.

DISABLED USA encourages the submission of articles for publication by all readers, especially disabled people. Articles should be eight to ten, typewritten, doubled-spaced pages, written in an informal style. We also welcome letters from readers for the RSVP column. (All articles appearing in DISABLED USA may be reprinted with or without credit.)

The Elephant Man...

best copy available

The Elephant Man

When a fiend is created, one that will terrify children and make adults recoil in disgust the monstrous fiend is usually disabled. It may be that an arm or a leg or an eye is missing. Or the villain may be mentally disabled. Usually, however the character that the reader or audience should hate is disfigured in such a way as to make it almost inhuman.

As in the following description:

"The most striking feature about him was his enormous and misshapen head. From the brow there projected a huge bony mass like a loaf, while from the back of the head hung a bag of spongy, fungus-looking skin, the surface of which was comparable to brown cauliflower. . . from the upper jaw there projected another mass of bone. It protruded from the mouth like a pink stump, turning the upper lip inside out and making the mouth a mere slobbering aperture. . . .

"To add a further burden to his trouble, the wretched man, when a boy, developed a hip disease, which left him permanently lame, so that he could only walk with a stick. . . . One other feature must be mentioned to emphasize his isolation from his kind. Although he was already repellent enough, there arose from the fungus skin-growth, with which he was almost covered, a very sickening stench which was hard to tolerate."

This quote ("Horizon," June 1979) is not a description of an ogre created in the imagination of some author. It is taken from the papers of an English surgeon, Frederick Treves. It is a description of one of his patients, John Merrick. And Merrick was not a villain, but an object of great charity. He was, in fact, a pet of some of the most important people in England.

Merrick, the embodiment of ugliness, was a kind and gentle man. Dr. Treves found him on exhibition in a sideshow. In the name of humanity, Treves took him into his hospital. In order to get money for Merrick's care, and for the hospital, he publicized Merrick's condition. London society responded to Merrick's physical needs.

But, in the process of helping this poor crippled freak to survive in comfort, they confused his emotions, and tortured him as much as those who had gawked openly and jeered him when he was in the small freak show. Yet, Merrick kept within himself a quiet dignity and tolerance of others. And these qualities, retained by a man in the face of such problems, affected Treves profoundly.

The story of Merrick, and his relationship with Treves and with others who came to give charity, is told in the Broadway production of "The Elephant Man." Written by Bernard Pomerance, the play contains all the facts of Merrick's life. And it dramatically presents the emotions that Merrick dealt with as he tried to separate intended compassion from resultant cruelty.

Merrick lived in the late 1800's, but the misguided acts of charity are equally valid in the late 1900's. What disabled

person cannot empathize with Merrick as he gets the gifts of royalty at Christmas, only to be ignored by most at other times?

Have not many disabled people, knowing little attention, been confused by adulation expressed by someone of the opposite sex? And further confused when the person offering this attention could not understand the recipient mistaking kindness for affection? Or, felt pain when offered love for a moment in an act of charity?

In "The Elephant Man," Merrick is a hero. And those who come to know him, and care for him in some fashion, are also presented sympathetically. The audience, and the critics, have been moved by the triumph of the human spirit which survived in such a poor container.

The play won a Tony award for the best dramatic presentation of 1979, and in the play Merrick finally wins recognition as a human being, not a freak. However, listening to audience reaction, one wonders if they have not been so warmed by the heroism that they have missed some of the complexities of emotions that the character contains. He is, perhaps, not so much a hero as a survivor.

Perhaps, the respect and acceptance which Merrick finally earns from audiences in this play come from the physical presentation of the character. Rather than use make-up to create a monster, Merrick is portrayed by a handsome, athletic young man named Philip Anglim. While the technique is most effective, and Anglim does a superb job in his portrayal of Merrick, one cannot help but wonder how the audience would have reacted if confronted by the real Merrick. Or a severely disabled actor portraying him.

Trying to analyze audience motives, however, cannot detract from a remarkable presentation by an actor. As Kevin Conway, portraying Dr. Treves, describes real pictures of Merrick, a light on stage reveals Anglim as Merrick, and, as the doctor describes Merrick, Anglim contorts his body to become the character. He retains this posture throughout the play, and alters his voice to illustrate Merrick's problems with speech.

Throughout the play, people come and go, reacting to the horribly disfigured man who has become a part of their reality. As the play progresses, Anglim becomes every inch Merrick, and one very quickly forgets that the actor in no way resembles the character. There is no sense of mimicry—Anglim becomes as much a monster in body as any makeup could create. The emotions he expresses are equally real and sensitive.

As a disabled person viewing the play, I was overwhelmed by Anglim's convincing performance. And, leaving the theatre, I was caught up in the enthusiasm of the audience and their attraction to Merrick. But, as time passes, the exuberance fades. More questions come to mind about the play's message.

Did Merrick really triumph? After all, as he accepted the world given him by his benefactors, he assumed his death—wasn't it his attempt to sleep in a "normal" position that suffocated him? Or was his disability progressive, and death inevitable? Did he understand completely that he had moved from a third class to a first class freak show? And, finally, did he have any choice—or was all his life manipulated by those around him?

These questions disturb because they are relevant today. How many severely disabled people determine the course of their lives? Do many just drift with the tide others create for them? And

An Interview With Philip Anglim

Philip Anglim is a tall, dark-haired, handsome, young and virile man with a steady gaze and a warm smile. He went to Yale Drama School and speaks without flaw, expressing himself in paragraphs rather than sentences.

While the impression is pleasant, it is also disarming. Because, in "The Elephant Man," Anglim portrays a deformed, ugly, repugnant freak. Recently, Anglim discussed his role as John Merrick, and described some of his feelings as a result of his portraying the man Merrick.

"Merrick spent four years in the hospital with Dr. Treves. The only record we have about him is the monograph Treves wrote before he died. Merrick had such a profound effect on Treves, that the doctor had to wait until after Merrick died before he could write about him."

Merrick appears to have had an equally profound effect on Anglim.

"Merrick had a spirit that was different. I can't explain why he was the way he was. But, to me, he was heroic, and epic. He educated people. He was primitive and honest.

"If he had a flaw, it was that he was too trusting, too vulnerable. But Merrick liked himself, in spite of everything. He saw honor in himself. He didn't accuse or blame. And he triumphed in the end. The wood model he so painstakingly carved of St. Philip's Cathedral—carved with one hand—is still on display in London. It's very intricate.

"I understand that portion of Merrick which is an outcast artist who becomes needed, but is always kept on the fringe. I guess we all feel misunderstood and not perceived as we would like to be. But Merrick transformed those who knew him. Eight hundred people a night in the theatre are affected by this spirit. There is something there we can all identify with."

Anglim is relaxed, calmly drinking coffee. When he speaks of Merrick, his voice and demeanor reflect the adulation that he feels for the man he portrays. His tenses change from past to present in mid-sentence as he describes a man, long dead, who is still very alive in Anglim's mind.

"Merrick was a real person, I don't have to make him real. I just have to show the whole person in a body that doesn't work. I use my voice and body to show that exterior. But there is so much more than that.

"I want to show the man inside. He is a man of humor and, also, compassion. He was very forgiving.

"In presenting Merrick physically, I try to imagine the weight he carried. And I use my voice to show the struggle he had in getting words out."

Anglim has drawn on more resources

the play disturbs a disabled person because the audience does not seem to recognize these questions as valid.

However, these questions did not occur to me immediately as I was leaving the theatre. They came later. And, hopefully, I am no different from the able-bodied members of the audience. Perhaps for others, also, these questions come later, after the joy passes.

If they do, and if people seek answers to these questions, then the play is more than a superb theatrical presentation. It is an important statement of what is needed beyond the quiet dignity of the individual.

—Diane Lattin

to portray the man he idolizes. The exterior man is his own creation, but he learned some of the inner emotions from a man who is now his friend. He explains:

"I worked in a play by David Freeman. He has cerebral palsy. As I got to know him, he became one of my heroes—like Merrick. David was, at one time, dismissed as an imbecile. He had to convince people he was worthwhile. And, I know the time involved for him just to write.

"I remember once we were at a restaurant. I was helping him put a straw in his drink. It bothered me because I knew people were watching. And they couldn't know the total person; they just saw me helping. With Merrick, I can show that total person that people don't see."

In response to a question, Anglim translates these feelings into the meaning it has had for his own life.

"This role, and knowing someone who is handicapped as a friend, has opened my eyes. I learned that appearances are deceiving. There are some extraordinary people trapped inside physical bodies that limit them in some way. I've learned to look at people who are different in new ways. And I hope, each night, that I am able to change the perceptions of people in the theatre in a positive way."

—Diane Lattin

The Theatre Unlimited

"All the world's a stage,
And all the men and women
merely players . . ."

—Shakespeare

As Michele Kunard stood on her front lawn in San Francisco's Sunset district, practicing slow motion movement exercises, a small crowd of curious neighbors gathered. "Hey, Michele, what are you doing?" a man called. "I'm practicing for Theatre Unlimited," Michele called back.

He watched a little longer, curious, then called again, "Hey, Michele, can you show me how to do that?" Pausing, she grinned. "Sure, come on!" Confidently, she began to show him some simple exercises. Some of the other onlookers joined in, then gave up after a few minutes. The movements were much more difficult then they looked.

Michele is one of eight developmentally disabled actors who, along with eight nondisabled actors, make up the membership of Theatre Unlimited. Three years old, Theatre Unlimited is a special project of the San Francisco Recreation Center for the Handicapped, and is dedicated to the expansion of the aesthetics of theatre.

Designed as a model for use in the fields of recreation, education, and the arts, the company's central goal is to develop an ensemble of disabled and non-disabled actors who work together.

Members of the company range in age from the early 20's to the mid-30's. They meet twice a week and rehearse for three hours, developing improvisational scores, and working on basic skills. A fundamental part of the theatre's work is developing exercises

which help to build trust and cooperation between members of the company.

In many ways, the company works on the traditional areas of actor training, such as movement, gesture, verbalization, sound, command of personal space, and the changing interrelationships of these elements.

But, they diverge from other developmental theatre companies in the use and context of these exercises. While the exercises encourage concentration, assertiveness, self-esteem and, ultimately, independence, the context is one in which disabled and nondisabled people work together to shatter old myths and create new models. Theatre Unlimited not only breaks down stereotypes, but tries to provide new images for both audiences and participants.

"I hold it truth, with
him who sings
To one clear harp
in divers tones,
That men may rise
on steppingstones
Of their dead selves
to higher things."
—Tennyson

Each year Theatre Unlimited creates an original dramatic work. The 1979 production was titled "Where the Sidewalk Ends." Set in an imaginary playground, the scenes were drawn from the poetic images of Shel Silverstein, personal memories, and new experiences. It goes like this:

In small groups, the actors enter, and slowly fill the stage with the mimed elements of a playground . . . a sand box, a set of swings, a teeter-totter, a frisbee game, a jump rope.

Then, when the playground is full of activity, an ice cream vendor enters and captures everyone's attention. The vendor leads the ensemble in a dance, where each member of the cast becomes a mirror of the vendor. A song invites the audience to join in the fantasy.

Other scenes feature different members of the company: The boy who wants to fly, the inventor whose light

"Ring in the valiant
man and free,
The larger heart, the
kindlier hand;
Ring out the darkness
of the land,
Ring in the Christ
that is to be."
—Tennyson

plugs into the sun, the dream of a water sprinkler on a hot day, and a solo by a gifted dancer.

The whole ensemble then does a contact movement improvisation. The dance technique stresses weight sharing, trust and risk-taking, energy transference, and continuous action or flow through a moving physical point of contact. It becomes a celebration of friendship and support as the performance comes to a close.

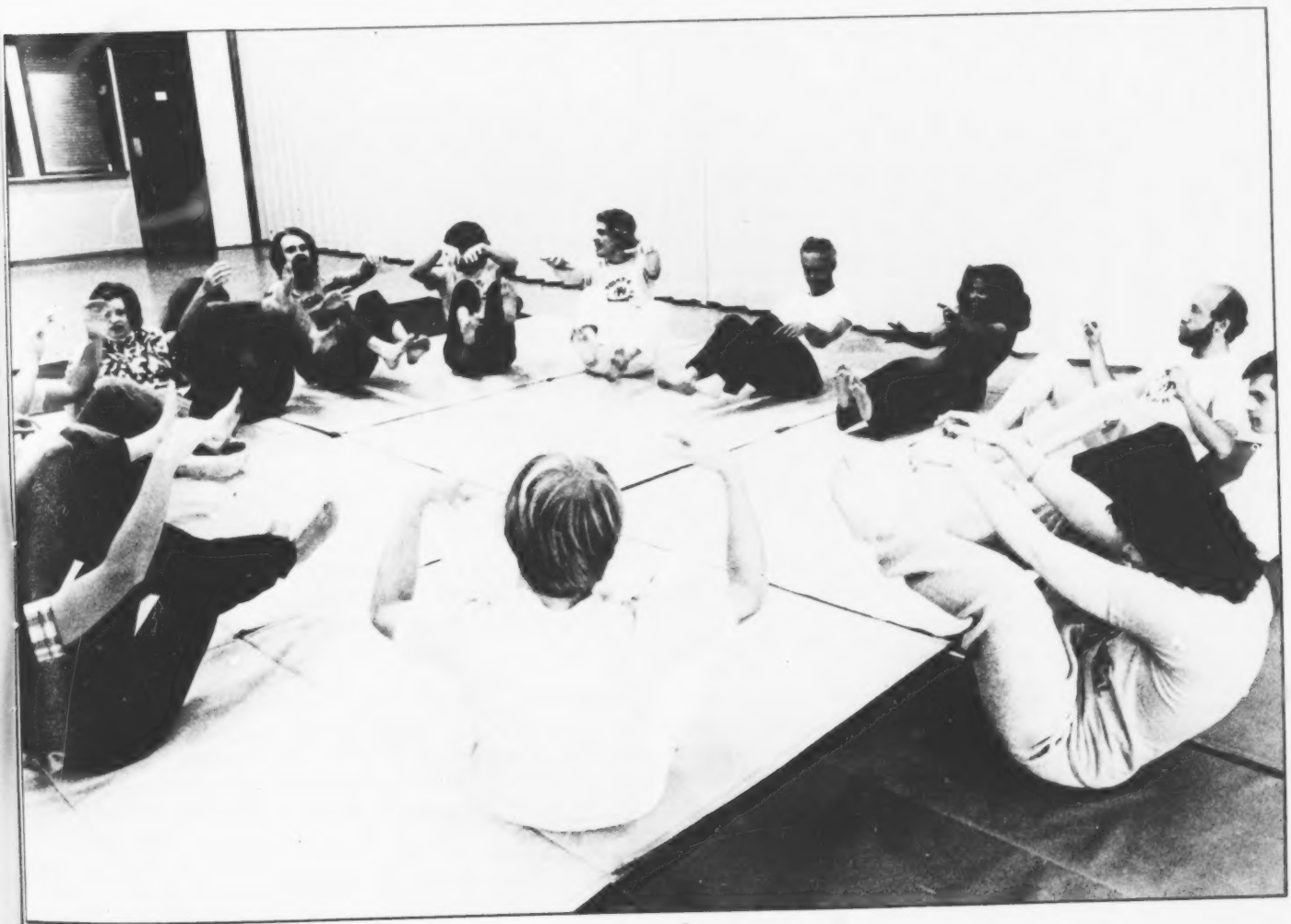
At the end of every performance, the actors come forward to talk with the audience and answer questions. Some of the most difficult questions come from children: "What's your handicap?" "How long have you been like this?" "Hey, which one is handicapped, and which isn't?" "How do you make a dance like that?"

The audience is then invited to participate in some of the basic exercises which make up the images of the performance. This workshop situation lets each member of the company share his or her expertise, and helps to develop leadership skills.

It also lets the disabled members of the company serve as positive role models for a wide range of people. The personal contact between the company and audience provides an increased social awareness for all involved.

Theatre Unlimited has found a receptive audience among students, parents, teachers, therapists, recreation specialists, and the general public. In the past year the company has performed throughout the San Francisco Bay Area, Los Angeles, and Washington, DC.

Audiences have ranged from partici-



pants in the National Very Special Arts Show, to evening programs for adults with disabilities at the San Francisco Recreation Center for the Handicapped.

Each member of the company has experienced creative personal growth. Not only are the disabled actors leading parts of public workshops, but often they assist and lead the daily dramatic programs of other disability groups at the Recreation Center. Perhaps the greatest area of personal growth has been in self-confidence.

The development of positive self-images in the disabled actors has helped to increase their abilities, and their desire to socialize, and has strengthened friendships with disabled and nondisabled people alike. The actors now raise questions, state problems, and express opinions, freely.

Instead of a simple "Yes, I liked it all", when asked about an evening's work, an actor might now say that some parts were more difficult than others; that this movement was painful, or that an exercise was particularly fun. Increased confidence has allowed them to receive criticism and rebound with enthusiasm, knowing that they can improve.

Along with higher levels of confidence, leadership, and communication, there has been an increase in responsibility by the disabled actors for the overall activities of the company. All members of the company have sought, and been given, greater responsibility.

This ranges from simple but necessary tasks such as preparing the rehearsal room every night, or assuming a high level of individual hygiene, to more difficult contributions such as helping to set up a performance schedule.

The most visible sign of creative growth by the disabled actors came at the beginning of the second year of rehearsals. With increased confidence, they began to suggest dramatic activities which could be worked on in rehearsal, and incorporated into performances and workshops.

Rusty was first with the idea of a dance about a girl whose jack-in-the-box comes to life late at night. Michele followed with the desire to speak to audiences about her personal feelings toward the company.

"And Thought leap'd out
to wed with Thought
Ere Thought could wed
itself with Speech"
—Tennyson

After seeing the success and support these ideas received, there was an outpouring of thoughts and imagination from every actor. This initiation and sharing has become the key to the continued artistic growth of the company.

Throughout the three years of the company's existence, financial support has been a problem. The San Francisco Recreation Center for the Handicapped and the National Committee, Arts for the Handicapped, along with thousands of volunteer hours, established the seed program.

The challenge now facing the company is to find support for its activities, which fill the gap between strictly artistic programs and those dedicated wholly to social benefits.

Currently, support is being received from the San Francisco Recreation Center for the Handicapped, the Evelyn and Walter Haas Jr. Fund, the Zellerback Family Fund, the California Arts Council, and others.

This support is the foundation for a continued existence that will allow the company's dream to come true. A dream most clearly expressed by Michele, when she was asked why she wanted to perform:

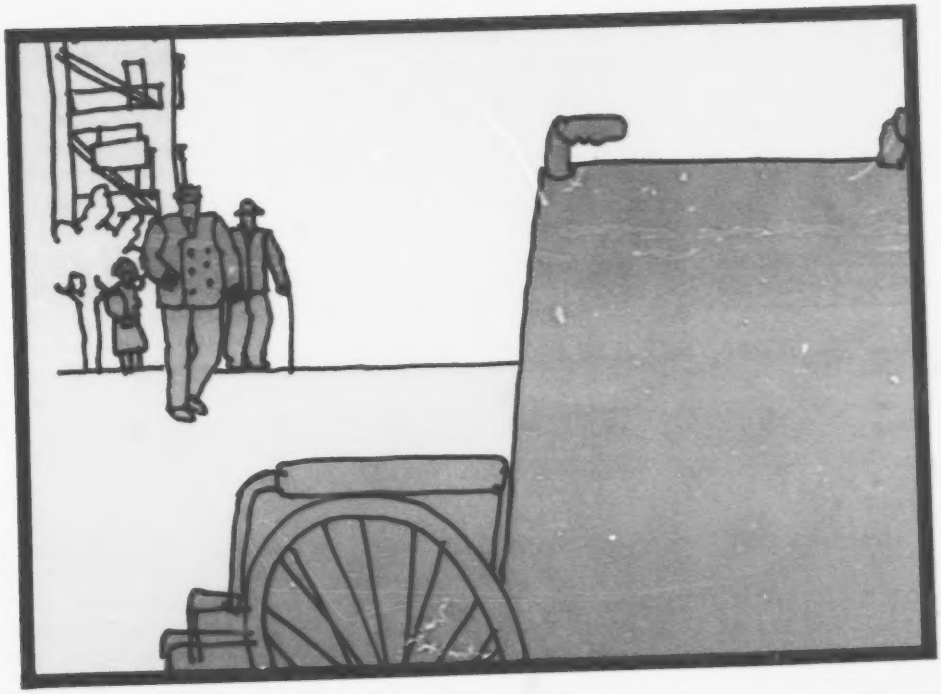
"I just want to show them what we can do."

—Richard Heus and
W. Randall McCommons

Mr. Heus and Mr. McCommons are members of Theatre Unlimited. For more information, write Mr. Heus at Back East Productions, 1660 Florida St., San Francisco, CA 94110.

Disfables for Ables

Combining Talents to Make A Film Which Breaks Down Barriers



The scene is Anytown, USA. There's a square, a courthouse, a cop or two, kids playing, a pompous leading citizen strolling, a train whistle in the distance, streets named Maple and Elm.

And into this everyday, ordinary scene rolls a wheelchair. Just a wheelchair. Shopkeepers, strollers, the children in the park, stare. It isn't as if they'd never seen a wheelchair before . . . it's just that none has ever been so bold as to ride down Main Street in broad daylight.

The town square is usually busy with people rushing to and fro. Today, those very same people go out of their way so as not to have to pass the chair. And there are some people who act as if the chair weren't there at all. A few laugh and point, and make fun of the tall chair with wheels.

This is the opening scene of a film that, with the grace of generous funding and friends, will be shot on location in a small North Carolina town next spring.

Star of the show will be the internationally famous mime, Graciela. Producer will be artist Maureen Trotto, who, early in 1979, wrote the script of "The Day the Wheelchair Came to Town," as part of a projected series of films, "Disfables for Ables."

Award-winning film makers, Gary Richman and Chaney Hales, of Chapel Hill, North Carolina, whose film on autism garnered so much acclaim, will do the shooting and editing.

The 26-minute film will be constructed so that commercial TV and public television can use it, and so that schools and colleges can air it as part of their educational programming.

"It's going to be a film for everybody," said Trotto. "The purpose," she emphasized, "is breaking down attitudes." In her mind, film, with its potential for reaching millions via TV, the medium with the most proven impact on those millions, was the way to go, although both she and Graciela had worked primarily in live theater.

Go back a few years. Trotto, an Ohio native, was studying at the Cleveland Playhouse and Museum of Art. She happened to be in the audience at a community theatre musical production in which mentally retarded people played important roles.

"It was fantastic!" she said. "Just great. I said to myself, why not use disabled people in more things? How can I work them into theater?"

Graciela, who studied mime with the incomparable Marcel Marceau, has often performed in institutions for disabled people. She, too, saw the outreach potential in using dance, mime, and music, all of which, taken together, would tell their story the

most effectively.

In seeking funding and public interest in their project, the partners found this: Many prospective sponsors looked upon a "handicap" film as pure documentary. Others were interested in an avant-guarde approach, but were not interested in anything "topical."

"People think the tow approaches are mutually exclusive," mourned Trotto. "And, forgive me for saying this, but a lot of films about handicapped people are not top quality. And we want to do a *top* quality film."

This past summer, the partners decided to put their ideas into action. Their first move was to get a small grant from North Carolina's Arts and the Handicapped Program to write the script "without having to worry about where our next meal was coming from," laughed Trotto. "In our business, it's difficult to survive in the first place. It was such a luxury to be able to sit and write the script I'd had in mind for so many years."

Thus, the first "Disfable" was born. Before writing the script, she and Graciela enlisted the aid of Jean McLaughlin, then director of the Arts and the Handicapped Program, to set up taped interviews with disabled people. Their questions ran like this:

"What would you like to see the public do to change attitudes toward you?" "What do you feel you would like to say if you had a forum of your own and plenty of audiences?"

The pair discovered that people in wheelchairs had different needs and desires from those of hearing and visually impaired people. Each disabled person held his or her own views of society's negative attitudes. The two women concluded that each fable would have to have a different approach.

They selected the wheelchair as the focus of their first fable because it is the most visible of all symbols of the handicapped community.

Besides interviewing disabled people, the pair viewed films; read reports done by the Regional Rehabilitation Research Institute on Attitudinal, Legal and Leisure Barriers; journals on blindness; publications of arts and the handicapped information services; and books on counseling.

Trotto set to work. An intense, joyous and creative woman, Trotto designed a charming fantasy, keeping in mind Graciela's considerable gifts, the wide audience she would reach, and steering away from the pitfalls of the too-heavy documentary or the cutsey-poo image a fable could impart under a less experienced hand.

The film is to be a combination of live action and simple animation. The live action will be pantomimed and the major characters will all be played by Graciela. She uses masks, or make-up and simple props, in her art of switching from the vain dowager to the portly mayor, back to an elderly citizen, and then to a child on a bike.

There'll be a narrator whose voice is the only one the audience will hear. Other characters will have had mime training and will play the roles of a cab driver, party guests, shopkeepers, and other small town figures.

Central to the film, of course, will be The Wheelchair.

Here's Trotto's synopsis of the plot:

"The day the wheelchair rolled into town, the townspeople stared from behind closed windows. They crossed the street to avoid the chair. Many simply ignored it. Some snickered. But the wheelchair went on its merry way. It was spotted around town doing the most ordinary things—flying a kite, mailing a letter, eating a hot dog at the corner stand.

"But what really stumped the townspeople was when they heard the chair say, 'Hello!'

"Why, there was a person in that chair—just like you and me!

"As the days wore on, the people of the town realized that things needed to be changed if they wanted the person in the chair to stay. And change they did. The good people worked hard, widening doorways, lowering shelves, and installing ramps. On the day that everything was finished, a town celebration was planned.

"The people worked in committees to make the celebration the best ever. But late that evening, as the committee discussed plans for the celebration, the chair picked up a small suitcase and left town.

"A little boy on his bicycle saw this and reported to everyone he met that the person in the wheelchair had left town.

"The people gathered in the square and looked down Main Street to catch a glimpse of the person in the chair. The people were sad and puzzled as they left the square for their homes. As they walked along, in a window here, and a doorway there, appeared other persons in chairs. Though it hardly seemed possible, it was true.

"They had been there all the time!"

Early in summer, Trotto and Graciela (Her full name is Graciela Binaghi. A native of Argentina, she has studied dance and mime since she was five, and is glamorous, dark and reserved in contrast to Trotto's ebullience.) invited a select audience of consumers, professionals and media people to a Raleigh church to see a preview of their "Disfable."

Trotto explained to the assembled group that her script was written with these things in mind: It raises questions about stereotypes of disabled and able-bodied people and about barriers existing in our society.

The production must accommodate the needs of hearing impaired and visually impaired people. There will be an interpreter in the cast. For breaks in

narration, there will be descriptive sound effects to cue visually impaired people into the action of the mime.

Braille copies of the script could be duplicated and made available to blind members of any audience upon request.

Trotto then read the entire script, Graciela donned her fanciful masks, and, with the uniquely universal body language of the mime, brought her society lady, her mayor, and all her characters, to marvelous life.

After the presentation, the audience had some suggestions for improvement:

Captions should be added for hearing impaired people who have some hearing but not enough to understand all the narration.

"Go easy on the 'us and them' approach," was a comment.

"The wheelchair needs a girlfriend (or a boyfriend, as the case may be). Romance and sex are attitudinal problems the script could handle nicely."

A most revealing comment came from a blind person: "Here, the chair does show that people don't see a handicapped person as a person first, but as a chair. Then, after the town recognizes the person, it becomes a person and not a chair. This is a common link for all handicapped people because we are so often viewed as nonpersons."

It was that comment that pleased the two members of the Graciela Mime Theater the most.

Now living and working in Winston-Salem, North Carolina, where the two met while teaching and performing at the North Carolina School for the Arts, Trotto's major concern is raising the $60,000 budget for the film. Because the Disfable series is the only one of its kind in the country, she and Graciela are optimistic of ultimate success.

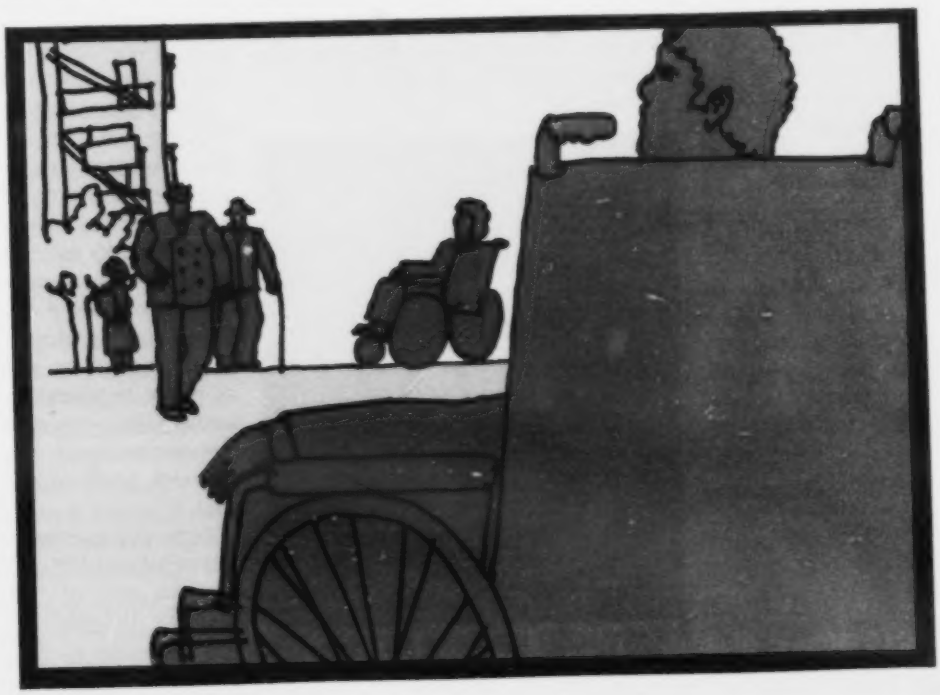
After "The Wheelchair," the two plan a film on hearing impairment, still keeping in mind that it must be produced so as to attract the magic mass audience. "The basic truth is that this is the most invisible of handicaps," Trotto said. "We have to keep in mind this question: What goes on in a person's head when he cannot hear?"

What goes on in the mind of any disabled person is a question society must confront right now, she added. For too long, the "rest of them" have taken it upon themselves to try mind reading. And it hasn't worked.

The impact of a beautifully crafted film with a cool message rather than the "hit 'em between the eyes" approach, is, in Trotto's and Graciela's view, the answer to changing attitudes and breaking down barriers.

—Bette Elliott

Ms. Elliot is a free lance writer.



Bernard Bragg

Delivering A Model Community Theatre Project

"When writers describe deaf persons, they inevitably say: 'He's a deaf artist . . . a deaf poet . . . a deaf dancer . . . a deaf so-forth.' " Bernard Bragg leaned forward, pounding the desk in front of him for emphasis. "Why? The person is an actor *who happens to be deaf*. It's as simple as that. In the arts, we are not disabled."

Bernard Bragg should know. An accomplished actor, pantomimist, and director, he is far more than just an excellent artist. Through his own skills, personality, and outlook on life, he has done a great deal to bring the beauty of sign language and the vitality of the deaf community to the attention of the world at large.

A deaf child of deaf parents, he played with hearing children from an early age. He used his body, face, and hands to communicate with them because he does not speak clearly. Wolf Bragg, his father, had a theatre company and, noting his son's unusual communication skills, often used him in plays. Bragg's flair for acting continued to be in demand while a student at the New York City School for the Deaf, and later at Gallaudet College.

Bragg graduated from Gallaudet with honors, and became a teacher at the California School for the Deaf in Berkeley. He obtained a master's degree in education from San Francisco State College.

In 1956, he read in a newspaper that Marcel Marceau, the famous French mime, was to appear in San Francisco. He attended the performance and sat in the balcony, watching people's reactions. He excitedly realized that all of the hearing people were raptly watching a silent performer.

After the show, he went backstage and wrote a note introducing himself as a deaf man who taught school and wanted to become a mime. "Where can I get training?" he asked.

Marceau invited him to audition the next day. Bragg performed two self-composed works. In "Noah's Ark", he played Noah and each animal. In "The One Man Orchestra", he conducted with his eyebrows and played all of the instruments.

Impressed with Bragg's potential, Marceau offered to teach him in the Ambigu Theatre in Paris. Bragg flew to Paris that summer and studied with the master of mime. He acquired the fundamentals of pantomime: clearness of expression, timing, proper breathing.

Afterwards, he came home, continued to teach, and performed at nightclubs. "The One Man Orchestra" was developed into a longer one-man show, "Silent Symphony". Bragg played all of the parts: Violinist, flutist, drummer, singer, audience member, conductor.

As the flutist, his fingers pressed imaginary keys and his lips curved around the mouthpiece, exactly in the correct spot. His body swayed with the music and weight of the instruments. He conducted with his eyebrows. He portrayed an audience member, totally absorbed in the music, looking from musician to musician, swaying to the beat of the music. The rhythm was so clear, one could almost hear it.

Then disaster struck the "orchestra". The singer lost his voice! Bragg's mouth and panicked expression made the scene obvious. The flutist couldn't get any notes on his flute, the drummer produced no beat. And the audience member looked around, puzzled.

Audiences in the night clubs thrilled to Bragg's performances, and often made special requests. Bragg became adept at impromptu improvisations as well, quickly devising such skits as "a one-armed paper hanger," "heart surgeon at work," "the day Lincoln was shot."

Television beckoned. In California, he appeared on KPIX on "Expression," under the title of "The Language of Silence". In 1961, he began a three-year nationally syndicated series of pantomime shows as "The Quiet Man" on "What's New", an educational TV show for children.

When the National Theater of the Deaf began in 1966, they needed talented actors. Bernard Bragg was a logical choice. Dramatic works were produced which combined sign language, body movement, and music to tell a story to both deaf and hearing audiences. Among NTD's repertoire were "My Third Eye," "Gilgamesh," "Songs of Milkweed", "Japanese

"Hearing people show emotions in their voices."

Kabuki Play," and "Tyger," by William Blake.

Bragg served as administrator, actor and signmaster, developing visually clear signs for difficult words. The NTD toured across the country, and around the world. According to one critic: "The gestures and mime of the actors are a ballet of the hands, rich in allusion and imagery which transcends the limited order of English grammar."

Bragg starred in "A Child's Christmas in Wales", shown on national television. His precise and fluid signs illustrated the poetic words of Dylan Thomas. For example, "blow up balloons," was illustrated by deep breaths, slightly bulging cheeks, and fingertips on the outside of the "balloon," moving in exact rhythm to his breath.

After ten successful years with the National Theater of the Deaf, Bragg took a sabbatical. Through the cooperation of the International Theatre Institute of the United States, he toured around the world, visiting cities in over 25 countries, including Moscow, Dublin, Madrid, Lisbon, Paris, Geneva, Zurich, Vienna, Belgrade, and Instanbul.

Not only did he give performances, but everywhere he went, he attempted to bring together deaf and hearing people. In India, he had both deaf and hearing children playing theatre games together. In Singapore, according to one writer who watched him, "Entertaining us on the stage was not all he did. He, in fact, managed to bring the hearing and deaf together, to feel as one group."

When he returned, Gallaudet offered him his present job as artist-in-residence. Bragg teaches courses and workshops at Gallaudet, outlining the techniques he has developed. The "visual vernacular," (in this art form, the legs do not move, but the eyes, face, and hands do the talking) and "sign-mime" (a combination of pantomime and sign language).

Through Gallaudet, he made a successful application to the National Committee, Arts and the Handicapped, for a grant to develop a Model Community Theatre of the Deaf.

"I'm grateful to Gallaudet for letting me do different things, letting me continue to grow in different capacities; allowing me to teach, to direct, to express, to be involved with the students, to create different projects. The College has given me complete freedom to do anything I want to do . . . ."

The National Association of the Deaf also gave some funds to the project. Hughes Memorial Theatre, an established deaf amateur theater group in Washington, DC, was chosen to become the Model Community Theatre, and its board of directors appointed Bragg as the artistic director.

A play, "Tales from a Deaf Clubroom," was developed by Bragg and Eugene Bergman. Many plots revolve around a main theme. A club treasurer steals money from the club treasury to support his son, who is a drug addict. He is caught stealing and is fired. But it so happens that he has a heart attack, and is brought to the hospital, and life goes on.

But the plot isn't important. What is important is that it will help us see people as they are, their dreams, their frustrations, their desires, their hopes, their wishes, the whole spectrum of human nature. The play was written to demonstrate what is meant by the term "deaf theatre". It deals directly with the life experiences of deaf people, and was written for audiences of deaf people.

The process of producing the play is as important to the deaf community as the product. The cast was chosen from workshops which were open to all area adults, and students from Gallaudet and the Model Secondary School for the Deaf.

The workshops served not only as rehearsals for the play, but as classes in signing styles for the theatre, acting, technical skills, and improvisation. Around 40 people attended and were divided in three groups.

In one workshop, Bragg told the group: "You are in a room. The walls will start to shrink and move inward. The ceiling will begin to descend. Soon the walls and ceiling will meet. Respond honestly to this situation." The people moved towards each other and ended up packed together on the floor.

Bragg noted, "I had expected the walls to move more slowly. You did act as an ensemble and received vibes from

"We show it on our face and our bodies."

each other which helped you to work together."

An actor added, "Everyone had a 'power decision' to make individually, then others accepted or rejected it. If all remained individualistic, the ensemble would not have worked."

In another exercise, Bragg oulined another situation: "This room is the same size as the last room. Move around. Enjoy each other's company. Suddenly you'll feel wetness at your feet. There is no drain in the room. Water will continue to rise... to the ceiling. It is cold, but you don't know how cold it will become, or how rapidly the water will rise. There are no doors or windows through which you can escape."

One actor dropped his cigarettes. He picked them up, felt their dampness, and threw them back on the floor. People lifted their feet, rolled up their pant legs. They talked to each other, asking what was happening, what they could do. A few began to worry about not being able to swim. One actor said that he would help them if they held on to him. As the water rose higher and higher, they began to move their arms and to hold on to each other. Eventually, one by one, they sank to the bottom and drowned.

Bragg said, "That was beautiful. Everyone became completely involved in the situation. At first, you were all playwrights instead of actors. You kept discussing the plot and how to escape. Then you stopped the discussion and reacted. But some of you drowned too soon!"

The workshops will benefit many people other than just the participants. The workshops are carefully recorded by notes and videotapes. Teaching materials may be developed. Bragg will also travel across the United States, giving four two-day theatre training workshops at community theaters of deaf persons.

At the National Association of the Deaf convention in June 1980, Bragg will work with representatives of community theatres of the deaf, and lead discussions on how to further improve "deaf theatre". Bragg hopes these efforts will help the concept of "deaf theatre" to become a stronger art form.

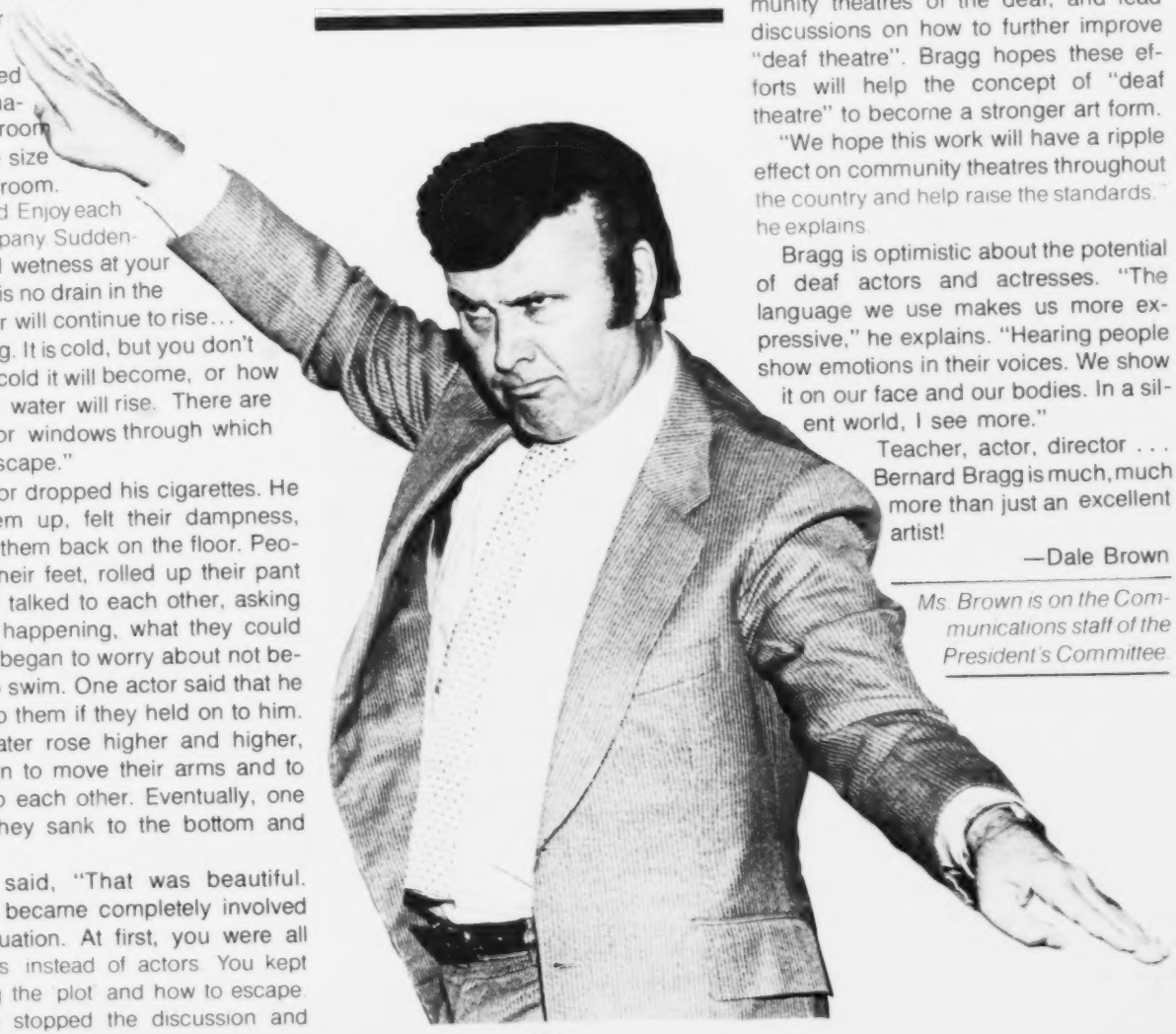
"We hope this work will have a ripple effect on community theatres throughout the country and help raise the standards," he explains.

Bragg is optimistic about the potential of deaf actors and actresses. "The language we use makes us more expressive," he explains. "Hearing people show emotions in their voices. We show it on our face and our bodies. In a silent world, I see more."

Teacher, actor, director . . . Bernard Bragg is much, much more than just an excellent artist!

—Dale Brown

Ms. Brown is on the Communications staff of the President's Committee.



Whose Life Is It Anyway?

The Play About A Disabled Person With A Different Kind of Courage

When disabled people are presented in theatrical productions, the characterizations usually follow a stock format. They are characters of only one dimension . . . courageous, and thankful to be living—at least by the end of the play.

These courageous, dependent characters give hope to their audiences. People leave the theatre with their hearts uplifted: "If these poor human beings, with all their problems, still have faith in the future and their fellow man, then how can I, a normal person, have any less faith?"

These handicapped characters provide a sense of security to others. They represent the attributes that people cherish—the willingness to continue against all odds and to overcome all obstacles.

And also, disabled characters have another feature which furthers this sense of well-being. They are able to overcome all obstacles, not only because of their own courage, but also because of the help of others. People can see good in themselves because they give help, and good in others who do likewise.

Then, along to Broadway comes a play that presents a totally different picture—"Whose Life Is It Anyway?" The disabled character in this play does not strive to overcome his disabling condition, and he does not want help from the people around him. At least not the kind of help they want to give. He wants them to stop doing the things that keep him alive, and allow him to die. The play is about his efforts to make his own decisions about his life, or death.

Tom Conti, who plays the disabled Ken Harrison in the play, won the 1979 Tony Award as best actor for this role. The play, which premiered in London before coming to Broadway, won critical acclaim and plays to standing-room-only audiences.

But, audiences leave this play, not with their hearts uplifted, but in a state of confusion. Some have even gotten sick or fainted. The reason is that this play, with all its wit and comic elements, has a very disturbing story to tell. It breaks all the rules for presentation of a disabled person.

The play does have a disabled character who is courageous. But not in the pattern we are used to. Ken Harrison displays his courage by fighting against everyone for his right to die. He has the desire to overcome the obstacles confronting him because of disability. But, in this case, the obstacles are the doctors who refuse to let him decide his future.

Harrison is not really questioning the future. He is not concerned about what will happen to him. He has his answers: he knows what the future will be for him. Having these answers, he wants no part of life. He questions the motives of those able-bodied people around him, and rejects a future dependent on the good will of others.

The setting for this play is Harrison's hospital room. Tom Conti does his entire performance from a hospital bed. Har-

rison is a severe qualriplegic, and, as this character, Conti never moves anything but his head. Conti gives a superb performance, in a role that is certainly a challenge to any actor.

All body language must come only from the face. Additionally, the actor must deal with the distracting problem that, for the length of the play, he cannot use his arms or hands, or move at all, to alleviate any discomfort that arises. This means that if the pillows are uncomfortable around him or his nose itches, he has to try to ignore it.

Just about everyone knows how impossible it is to ignore something like an itching nose—it only gets worse. For this reason, one concession has been made to Conti's comfort, a concession that does not detract from the characterization. A "panic button" has been placed near the actor's hand under the bedcovers.

If Conti becomes distractingly uncomfortable, he pushes this button. A light goes on backstage, and as soon as the plot will allow, help is sent out. The help comes in the form of a minor character, such as a nurse or aide, entering the scene on some pretext. Then, as Harrison, Conti asks that the pillows be fixed, the fan turned on, or his hair be brushed out of his face. Alternatively, a major character, like one of the doctors, is alerted to the fact that Conti needs help, and fits it into the scene.

In the play, Harrison deals primarily with two doctors—Dr. Scott, portrayed by Jean Marsh (Emmy-award winner for "Upstairs, Downstairs") and Dr. Emerson, portrayed by Philip Bosco. Dr. Scott has some sympathy for Harrison's desire to decide his future. Also, as a woman, she is confused by her feelings for this handsome, bitter young patient. Dr. Emerson is less sympathetic and more representative of the God-Doctor complex.

Bosco describes his character in this way: "Dr. Emerson is seen as a pompous prig. The play puts him down. He is representative of doctors who see themselves as coming down from heaven, deigning to decide life and death.

"The play is slanted to the patient. There have been a lot of comments commending the playwright for making people aware of the problem. But, I wonder if the play could lead the audience to feel that it's not worth the effort to create meaningful lives for people with severe disability. Will people feel that it's easier to let people die, that it saves time and money?"

Bosco clearly believes in his character, which, perhaps, makes his performance all the more believable.

"I'm in favor of the doctor. There is cowardice in Harrison. A person who would take his own life is mentally unbalanced or doesn't have the necessary spark. 'Whose Life Is It Anyway?' has a 'Catch 22.' Given enough time, the doctor could win Harrison over. But, he needs time to bring Harrison out of his depression. Once past that hurdle, he could lead a meaningful life. But, Harrison wants to take that time away from the doctor.

"I agree with the doctor. We should keep people alive, no matter what."

These are the same kinds of feelings that are evoked in the audience. By the time the theatre empties, most of the people leaving are in the middle of heated discussions about whether the doctor or Harrison is right.

"One woman came back to see the play several times," Bosco recounts. "She said she couldn't remember ever discussing any play more."

"Whose Life Is It Anyway?" is an important play. It is important because it presents an issue that is topical and controversial. But, what makes this play so particularly disarming is that it deals with a sensitive topic through comedy.

Brian Clark, the author, and Conti both spent time at Stokes Manville, England, getting ideas from disabled people. Clark draws his dialogue from these conversations, including the sometimes bitter, sometimes self-deprecating humor that he heard in this rehabilitation hospital. Conti's experiences allow him to translate this material perfectly, reflecting in his face and manner the emotions that are not written into the script.

What all this means is that, along with the moral issue, audiences get a new picture of disabled people. One critic has suggested that the popularity of this play indicates that there is a sickness in America.

He was, perhaps, reacting in part to a disabled character who is not all sweetness and light. Is there something wrong with a handicapped character who doesn't rise above the earthly problems confronting him? The critic seems to feel there is something wrong with an audience that finds this character witty, attractive, and sympathetic.

What the critic didn't realize is that, while the presentation of such a character on Broadway is a new phenomenon, the existence of disabled people who are like Harrison is nothing new. Probably few are as desperate as Harrison, but most are, at times, as confused. All are complex. Hardly any are like the wooden presentations of disabled people that have too often been seen in the past.

There is nothing wrong with America. That is reflected in the audience's appreciation of this play. In fact, there might be something right. It may be that America is finally growing up with respect to disability. People are learning to appreciate a disabled person as a total human being, and not just one big, quivering mass of courage.

Now, as soon as we develop and utilize disabled actors to do the on-stage work, disabled people will really have made an impact on Broadway.

—Diane Lattin

Theatre and Disability: An Artistic Program With Social Benefits

Until relatively recently, the active involvement of disabled people in the performing arts was considered either unacceptable because of apparent physical problems, or acceptable only within very patronizing limitations. To echo what has been said: "A cripple must be careful not to act differently from what people expect . . . they expect the cripple to be crippled."

This unwillingness to break the misconceptions of disability is seen in the

unwillingness of the media to concentrate on anything but the "succumbing" stereotype of physically handicapped people. Thus, TV coverage of activities that disabled people do well is minimal.

In one field of the performing arts, the live theatre, an attempt has been made to confront these attitudes so that an audience is forced to apply a criterion normally reserved for able-bodied people in theatrical performances.

Audiences are aware of the physical reality of actors on stage—one is taller than another, one is older than another—but these facts are only of incidental interest. However, they often give clues as to the role of the specific actor, i.e., he is playing an old man.

The impact of physical disability is inevitably considerably stronger than that. How can the disability be prevented from becoming the overriding factor in the audience's perception of what is taking place on stage? There are perhaps two approaches.

First, there is the common denominator approach. If something common to all of the cast is obvious, the audience will realize this, accept it, and dismiss it. For example, a company of black actors. The fact of their blackness is apparent and obvious, and the total commonality of this reduces the significance.

Thus, if a black company wishes to perform Hamlet, the audience will, of course, realize the unlikeliness of a black Dane. However, they will quickly attune themselves to the rules of this particular game and, having established them, apply their normal criterion of judgment to the performance.

This might be possible in the case of disabled actors if it were not for the fact of one misconception: people still question the physical ability of disabled people.

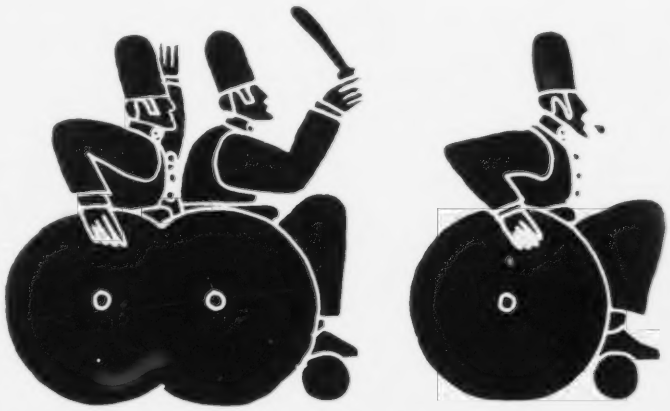
Fifty years ago, an all-black Hamlet cast would have constituted a similar problem to an audience. The blackness of the cast, and the inability of the audience to overlook that, would have created an unacceptable situation. Now such a performance would be viewed using the accepted and usual tools of criticism.

There is another way of coping so that an audience can be reassured that its senses do not lie. That is to use, deliberately, the specific disability as part of the play. Here, no attempt is made to pretend that it does not exist. It is there. And it is there as a necessary and integral part of the actor's characterization.

A wheelchair is not a prop in the sense that it gives support, but a prop (property) in the theatrical sense (i.e., that it furthers the action of the play or the understanding that the audience has of that role). The disability is integral and complementary.

Once this basic concept is established, a director or writer can think positively about disability. Questions such as how a wheelchair can speed the action, or, in what ways being on crutches can support a characterization, can be raised.

For example, being in a wheelchair gives a very different slant to mobility. It



is faster, smoother and more subtle than walking. Only in a wheelchair can a person move right across stage without any apparent effort, simply by pushing once and freewheeling. This can be used effectively. The speed of a chair allows literal chases (Keystone Cops) to take place on stage. Crutches can be used as a reinforcement of the color, the shape, and the significance of a costume.

If these ideas are successfully implemented, the audience is forced to view the performance as a piece of theatre, to be judged by the same criterion used for any performance.

If an audience, after a performance, can say, "that was terrible," that is considerably more satisfying than if they say, "didn't they do well, considering."

The aim is not to produce terrible theatre; but the chance of being terrible is allowed to exist within the judgement of the ordinary theatre-going public.

Having established in theory that disabled actors can contribute to the performance of a play, two further questions are raised. First, does this mean that in any one production all of the cast has to be disabled? Second, which plays lend themselves to this sort of interpretation?

I think that there is a potential in productions using both able-bodied and disabled actors, but the scope is reasonably limited. Certainly there are enough scripts in film, TV, and theatre that have a character with a disability in them; and there are also isolated examples of people with disabilities making careers as performers.

But there are also parts that could be played by a disabled person without changing the impact or concept of the play. Shakespeare, in particular, has several parts that call for a disabled actor—Caliban or Richard III are examples.

There are other parts that are not ostensibly written as disabled characters but could be played by a disabled actor—Polonius, Duncan. The only, but most important, rationale that needs to be applied is whether or not the actor is good enough.

But it is difficult to imagine a director producing a play using more than one disabled actor and maintaining viability, without changing the impact and focus of the play quite dramatically.

A solution is to change the focus of the play. Perhaps the easiest way to do this is to use actors who are all physically handicapped. The number of plays that one can do this with is certainly not all-embracing. One has doubts if realistic situation pieces could be done, but other plays certainly could.

One such is "Chairs," by Eugene Ionesco, a play calling for actors in wheelchairs. Most of Samuel Beckett's and Harold Pinter's plays lend themselves readily to this kind of interpretation also. Many other playwrights, whose interests are more surreal than real, also lend themselves to the use of disabled actors.

There are endless possibilities for exploration and experimentation. The most important thing is to have intellectual consistency. Theatre is the creation of an illusion. If that illusion is based on a solid rationale, an audience will accept it unquestioningly.

The preceeding, highly specialized concept of theatre, arose because of the demands of disabled students while I was teaching at Hereward College of Further Education in Coventry. This college is solely for physically handicapped students. Some expressed interest in an active involvement in theatrical performances, and, over a series of years, the above theoretical argument evolved from direct experience.

Initially, productions were very much on the level of revue sketches, designed to entertain other students and staff. However, from this grew poetry reading sessions and vocal experimentations. The first real break with the superficial revue format came with the production of the medieval mystery play, "Everyman".

The ritualistic and stylized concepts used in this play lent themselves well to performances by disabled actors. "Death" was performed by a student in an electric wheelchair. The whine of the motor, and the threatening shape—he was covered by a black hood—complemented the characterization. Other actors also used specific disabilities as integral parts of the characterizations.

"Everyman" was done for an invited audience, an audience which was there because of personal connection with the cast or the college, not because it normally went to the theatre.

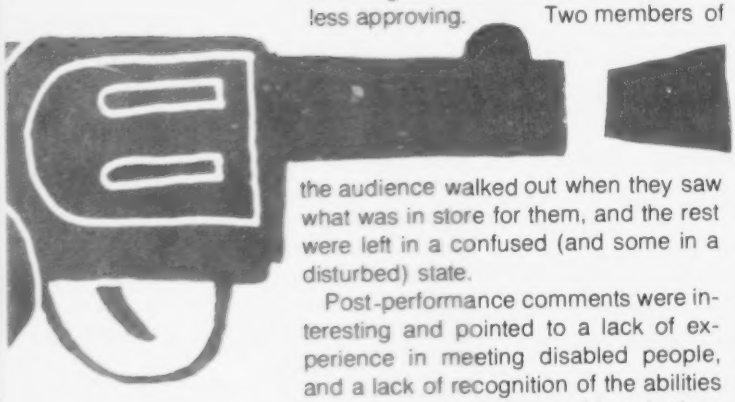
Our next step was to mount a production that would be shown outside the college buildings, to an audience that was not familiar with disability. With that in mind, it was decided to devise a play about disability, to try and explain what it meant to the individual, and how he or she perceived social reaction to disability.

A series of scenes evolved during rehearsal, and, in time, became sufficiently developed to be structured by a script. An initial production for an invited audience was revised, recast, and largely rewritten. In Spring 1972, the show, "Ready Salted Crips," was ready for performance.

However, during the welter of planning, rehearsing and technical preparation, much of the impact of the subject matter became weakened. Also, in many ways we were not prepared for the impact that the content would have on the audience.

The first performance at Canley College of Education, Coventry, was greeted with uniform encouragement. A review in the College paper read: "The real triumph of the whole performance was that we quite forgot to feel sorry for any of the cast. They shook up our complacent attitudes, involved us in their problems, and challenged us to be sympathetic if we dared."

The next performance was at Mid Warwickshire College of F.E., Leamington. Here the reaction was far less approving. Two members of



the audience walked out when they saw what was in store for them, and the rest were left in a confused (and some in a disturbed) state.

Post-performance comments were interesting and pointed to a lack of experience in meeting disabled people, and a lack of recognition of the abilities of such people. Some could not believe that a girl who was an athetoid spastic could have acquired the necessary entry qualifications for University. Others could not think of the cast as being anything but "different."

Further performances were given at Coventry Cathedral, the Loft Theatre, Leamington, and at a conference for Headteachers and Administrators in Special Education. All performances were followed by question and answer sessions. It was here that many of the fears and preconceptions of the audience were discussed in a manner that would have been quite impossible before the show.

However, the main thesis, that disabled people could produce competent, viable theatre, had still not been fully tested. As a precursor to mounting a production that did not have the subject of disability as a central theme, a short pub entertainment was devised, based on a traditional mummers play.

This was a short sketch (about seven minutes) enacting the traditional story of King George and the Turkish Knight. No attempt was made to develop the characters using actors' disabilities as complementary elements.

We took it to seven or eight pubs. Although permission had been obtained from the landlords, the patrons at the bars had no inkling of what was in store. The chief impression gained from this experience was the marked difference between middle class pubs and working class pubs.

The former reacted in a very negative way. Embarrassment tinged with pity was the norm. The latter were far more willing to enter into the spirit of the story, to ignore the fact of disability and cheer the hero or hiss the villain. That we played the working class bars late at night might have been a contributing factor—they had been drinking longer!

We then moved on to a production that was meant to be taken as straight theatre, and to explore the avenues of using disability as an integral and complementary part of acting. The play chosen was Pinter's "The Dumb Waiter".

The play has two acting parts, and tells the story of the relationship between two men, hired killers, who are staying in a basement, awaiting fresh orders. The orders are transmitted through a serving hatch (the dumb waiter). As the basement used to be a kitchen, the orders are randomly mixed with requests for food. The total effect is ominous, but funny.

One of the actors was in a wheelchair, another on crutches. The play starts with one of the characters finding matches in his shoes. This was done, deliberately playing up the grossly shortened legs of the actor.

Another scene involves the preparation for a killing. The crutches of one actor were used as part of the equipment needed to mount a gun.

The play ends with one of the characters entering, having been stripped of his gun and all symbols of authority. He has become the victim. The actor in question crawled in, out of his wheelchair. The purpose was to reinforce Pinter's image of vulnerability using the resources available. This is one way that a specific theatrical situation can be exploited and heightened by

a disabled actor.

The reaction of the audience to this production was again encouraging, for rather than talking about the performance of the disabled actors, they talked about the play and what it meant.

When asked directly about the effect of the actors being disabled, people recognized that this had become part of the play, and that disability, in itself, had not been contradictory or separate. Comments that some of the devices had not worked highlighted the fact that a normal rationale could be applied.

This production gave hope that the theories were not just wishful thinking. I then had the opportunity to go to the United States for a year. At the Rehabilitation Education Center, University of Illinois, I again had the opportunity of developing plays using disabled actors.

Much the same theatre history was reenacted in America—the proposition of the idea, the arguments for implementation, the involvement of the student body. After discussion it was decided that a sound start would be to rework the play about disability.

This was seen as a starting point for further exploration and experimentation. A cast of seven was formed. Rehearsals and the rewriting of "Ready Salted Crips" got under way.

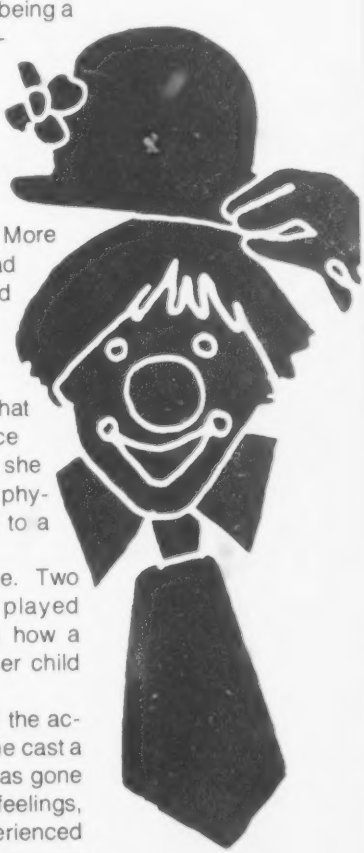
The title of "The Side Show" was taken, as we felt that a physical handicap is still often something to be stared at. The wheelchair is sometimes of more importance on initial contact than the person in the chair. The analogy with a freak show at a circus was easily made.

At the start of the play the characters were seen as objects, as things to be looked at, or as performers expected to do tricks. By the end, the personalities of the individual performers emerged to break through the stereotypes.

To reinforce this, all the actors started with assumed "circus" names: The Great Spasmo, The Obnoxious Gnome, The Gorillaman Earl Solomon O'Flynn. In the last scene of the play, all the cast used their real names—"I'm Ronda . . . I'm Bob . . . I'm Barbara." Similarly, all the cast started in clowns' hats, fulfilling the stereotype of the buffoon, the jester at the King's court. In the last scene they removed their hats and became themselves.

The play is essentially a satire on many of the social attitudes perceived as being commonly held. Employers, for example, might rationalize that they do not employ a disabled person on the grounds of insurance problems or peer acceptance.

"The Side Show" exaggerated this into a deliberate campaign to "Hinder the Handicapped," or "Kick a Cripple". Socially acceptable employment for a disabled black man was seen as being a "blues singer". The logical extension of this was that the more disabled he was, the more successful a singer. So he became a blind, crippled, black, epileptic, paraplegic, amputee.



Another example was the story of "Beauty and the Beast". More than one member of the cast had mentioned that their able-bodied peers expressed surprise at their "dating" able-bodied people.

In our play, Beauty found that she didn't get a handsome prince when she kissed the Beast, but she did learn that things other than physical normality contribute most to a relationship.

The play was not all satire. Two scenes in particular were played realistically. The first examined how a mother felt on being told that her child was cerebral palsied.

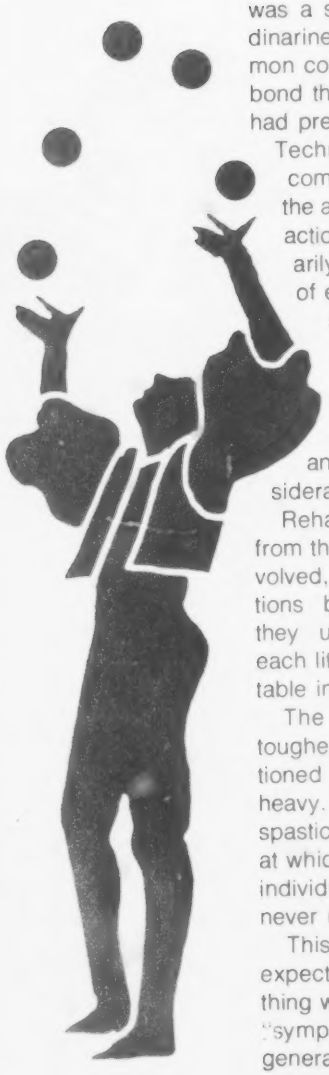
The second scene recounted the accident that left one member of the cast a paraplegic. The incident itself was gone into in some detail, as were the feelings, thoughts, and relationships experienced after the accident. The scene was very personal, and not intended to be a general comment. But certain things emerged concerning the affirmation of life that do have general significance.

The play had a chronological theme in that succeeding stages from birth, parental reaction, miracle cure, to special school and employment were followed. But the format was loose, and allowed some inconsistency. Not all the scenes fitted into the analogy of a side show, the accident being one such, but it was felt important to include it. Previous experience had indicated that this scene had immense impact on an

audience.

This actor was very much the audience's representative. She was part of "us" (in audience terms) before the accident. After it, she became part of "them". This identification pulled the audience into a personal involvement with "The Side Show."

The actors no longer represented "them." They were all part of "us." If this was in any way achieved, then the play was a success: The normality, the ordinariness, the myriad of points of common contact and experience, created a bond that the visual impact of disability had previously made seem impossible.



Technically, the shows ranged from competent to quite good. People in the audience were divided in their reactions. Feedback was extraordinarily positive, not only in the sense of enjoyment, but also in the sense of this being a strangely singular emotional experience.

Dividing the audience up between those associated with the rehabilitation program and the others, one found a considerable difference of reaction.

Rehabilitation people found it funny from the start. They knew the people involved, and were familiar with the situations being reenacted. Undoubtedly, they understood the significance of each little scene, but they were comfortable in finding them funny.

The other group found it much tougher going. Several people mentioned that the start was particularly heavy. It just was not funny to watch a spastic trying to juggle. The specific time at which this group relaxed varied from individual to individual. Some probably never relaxed at all.

This ambivalence was probably to be expected. However, the most reassuring thing was that no suggestion of "pity" or "sympathy" was heard. Perhaps the general consensus felt by this group was summed up by one dormitory advisor, who said that she had to go away and think a lot.

This sort of production has social value. The message was very clear. The implications are far-reaching. The theatre, because of its immediacy and its personal intimacy with an audience, is an ideal medium for encouraging attitudinal change.

This is not to argue that all productions using a cast of disabled actors should preach about the abilities and normalities of the disabled community. That would grossly limit the scope of work possible and deprive disabled actors of opportunities in exploring and developing talents in a range of parts nearly as wide as is open to able-bodied actors.

Indeed the production of plays not deliberately written for disabled actors, but performed with a proper regard to theatrical disciplines, would have an implicit message every bit, if not more, effective as "The Side Show."

It is necessary to sustain and develop this work for the benefit of disabled actors, and most particularly, for the benefit of the community. One aim would be the foundation of a National Theatre for the Disabled which would employ, on a professional basis, a company of actors and all the ancillary staff needed to run a theatre.

Its purpose would be to explore and develop works of theatre that could be produced and shown throughout the country, not only playing at local repertory theatres but also schools, colleges, and universities.

The deliberate policy of taking the talents of disabled people to the populace at large is a positive way of fostering acceptance and understanding.

By emphasizing a form of activity which is common to the majority group interest, in this case the theatrical process, the similarities are highlighted. This encourages a reevaluation of attitudes and a reexamination of many of the myths associated with disability. Research can point to the "ordinariness" of disabled people, but only positive example can bring it home to a wider audience.

—Richard Tomlinson

Mr. Tomlinson is assistant advisor on the education of handicapped students at the Open University, Milton Keynes, England. His newest theatre group will perform at the World Congress of Rehabilitation International, in Winnipeg, Canada, June 22-27, 1980.

The Kids On The Block

Meet the "Kids on the Block." Mark Reilly is a guy who has cerebral palsy and uses a wheelchair, which he calls a "cruiser." Mark is limited in some ways, but boy, does he play checkers like a champ!

Brenda Dubrowski is "normal" . . . except she's a bit overweight! She's a good friend of the other kids, and often joins in activities with one or more of them.

Ellen Jane Peterson is a veterinarian's assistant. She's 17 years old, and has Down's Syndrome. Ellen Jane is really good at her job and has a boyfriend named Reggie.

Renaldo Rodriguez is almost totally blind, but can tell the difference between light and shadow. He has lots of interesting things, like a braille watch, a special buzzer ball, and a dog named Joe Dog.

Melody James is another "normal" kid. She wears glasses, and has four brothers who tickle and tease her a lot.

Mandy Puccini is deaf. She knows sign language and loves to dance. She has two sisters who can hear and a cat named Sneakers.

The "Kids on the Block" are a group of incredible puppets, some handicapped and some not, which help kids to understand different disabilities, and what it's like to have them.

Created by Barbara Aiello, a former teacher of handicapped children, and a consultant and writer in the area of special education, the "Kids on the Block" are three feet tall and wear real kids' clothes and shoes, helping children relate to them, and talk to them more freely than they would with adults or other children with disabilities.

There are two important goals for the "Kids on the Block." "First," Aiello says, "I want to teach children about handicaps in a non-threatening and unpreachy fashion. Second, I want to show non-handicapped children how to develop positive relationships with their handicapped peers. The puppets show them how they can be friends."

Originally planned as an educational puppet show, appearances were so successful that Aiello decided to package the puppets as a kit.

Ideally, the kit (including the puppets, props, scripts, chattabout cards, and braille books and cards) is purchased by a school or school district. Individual

teachers plan for a time, say once a week, to talk about one disability, the next week moving on to another disability. When that class is finished, the district can make the kit available to another class in its system.

Aiello writes all of the scripts for the puppets, which are developed from the questions and concerns of non-disabled kids. All of the script material is critiqued by disabled children, adults, and parents of disabled children before being incorporated into the kit.

A typical scenario goes like this: Two teachers select a script, get the puppets and props together, and do a show for a classroom. Afterwards, the children ask the puppets any questions they want. "The questions," Aiello reports, "are getting better and better. One little girl asked Renaldo: 'How did your mother feel when she found out her baby was blind?' "

In this kind of educational effort, it's important to talk to kids on their own age and intellectual levels. Puppets can do this without sounding preachy or condescending . . . just like one of the kids.

Aiello explains: "One small boy asked Mark some questions about multiple sclerosis. Mark said, 'I don't know . . . I have cerebral palsy, not multiple sclerosis. You'll have to ask someone who has multiple sclerosis about it.' The puppets are like other kids. They don't try to know everything. If a child asks another 'kid' about blindness or braille, that 'kid' will say, 'I don't know about blindness. You'll have to ask Renaldo that question!' "

Aiello finds that a good age range for this kind of educational effort in attitude building is 8 to 12 years old (third to sixth grade level). Children younger than that are often not yet aware of attitudes, name-calling, prejudice.

While primarily designed for non-handicapped children in mainstreamed classrooms, Aiello has also used the puppets in resource rooms, and special ed classrooms. The puppets are very helpful, she finds, in helping the kids to learn to feel positive and unique about themselves.

The purpose of the non-handicapped puppets is to provide "kids" that the audience can easily relate to. The "normal" puppets can express many of the fears and concerns of the audience, and thus provide a way for the handicapped "kids" to deal with the situation. They also show that it's okay to be friends with disabled kids, and that the disabled kids have many friends, not just other kids with the same disability.

For example, says Aiello, " . . . Melody verbally expresses the fears of many a child when she blurts out, 'Gee, Mark, I don't know if I should play with you. What if I catch cerebral palsy? My mom would be really mad!' As Melody learns more about her new friends, so does the audience."

Also, Mark has a "normal" brother who talks about things like feeling jealous because Mark gets so much attention, how it feels to have a handicapped brother, and how he's glad he doesn't have CP. Thus, the kids in the audience can discuss these feelings, and learn that they are normal feelings for any child.

The puppets were constructed by professional puppeteer, Ingrid Crepeau, who has won two regional awards for design of puppets on a Washington, DC, children's television show, "Sneakers."

During the past 18 months, the "Kids on the Block" have traveled across the country, performing for groups of children and adults. ABC's "Good Morning America" featured the "kids", and they've also appeared with Ed Walker (a blind performer) who hosts "AM Washington," in the Washington, DC-area.

Thanksgiving weekend, they were featured with Gary Burghoff on a CBS television special, which was aired nationally and was repeated twice.

The "Kids on the Block" are truly animated, entertaining, appealing. Children and adults of all ages are fascinated with the shows. But, as Aiello stresses, the puppets are not intended as entertainment. They were primarily developed as an educational tool, to help children learn about disability, and how they can be friends with disabled children.

Helping childen to develop positive attitudes toward people with disabilities, while utilizing the children's own healthy curiosity, is sometimes difficult to do when dealing with disabilities. But for Barbara Aiello and the "Kids on the Block," it really isn't very hard at all!

—Muriel Horton-Strassler

For more information on purchasing the "Kids on the Block," contact: The Kids on the Block, Suite 1040, The Washington Building, Washington, DC 20005. (202) 737-7780.

The Source Book

An Invaluable Resource Guide for Disabled People

Scarcely a day passes that someone—somewhere in the world—doesn't ask a question relating to a disabling condition, or to sources of assistance for a person who has a disability.

The Source Book for the Disabled, edited by Glorya Hale, and published by Paddington Press, is one of the newest and most comprehensive books to come along to answer the many questions asked by disabled people, their families, or friends.

The *Source Book* is a compilation of several contributors. Pat Barr, Gertrude Buckman, Susan Goodman, Heather Jimenez, Vivian Naylor and George Seddon, and a number of other individuals and organizations, both here and in Great Britain, have helped to develop this invaluable resource guide.

The *Source Book* is billed as "an illustrated guide to easier, more independent living for physically disabled people, their families and friends."

It is more than that! This is a practical book. It suggests practical ways of doing things, taking into account that a disability doesn't prevent a person from completing a task, or from developing a method that works well for him or her.

Using a common-sense approach, the book examines many subjects in depth, and from many angles. It presents workable options, and allows readers to choose the methods that are best suited to their needs. The book contains over 600 drawings of aids and equipment that can help make life more independent for people with physical disabilities.

The first chapter asks the question: "Disabled or Handicapped?" It covers aids that help with walking, the telephone, communications, reading, writing, speaking, electronic devices, alarm systems, depression, fatigue, medical care, attendants, loneliness, love and independence.

One section of this chapter stands out: "Asking for Help." That's not the easiest thing to do, even for able-bodied people, as the book points out. There are two sides to the coin: On one side are people who feel they must do everything for themselves. On the other side are people who sit back and accept all the help they can get.

The *Source Book* suggests a balance between these two extremes. And it suggests ways for dealing with—perhaps coping is a better word—those well-intentioned helpers who know not what they are doing. The book suggests: "Don't turn against these well wishers. What they learn from you about helping may help them with another disabled person some day."

In the chapter, "Your Place in the Outside World," you'll find a discussion of public attitudes, the roles of the media in shaping acceptance, access, public and private transportation, the economic aspects of disability, rehabilitation, education and employment.

The employment section traces the history of efforts to open doors to jobs for handicapped people. It examines the impact of laws and regulations on the employment of handicapped persons. And it includes some do's and don'ts to help disabled job applicants present themselves in a favorable light.

Other chapters deal with your home and how to adapt it, handling personal needs, sexuality, the disabled parent, the disabled child, and recreation and leisure.

There are two other important sections in the book. One is called the "Disablers," and defines a number of disabilities in plain English.

The other is called "Resources." In this section, you'll find a sampling of the kinds of organizations which are concerned with specific disabilities. It contains a listing of some general public and private agencies and organizations concerned with—or working with—disabled people. It also has a listing of general reference books and periodicals, as well as sources of information on a wide variety of topics.

The *Source Book* is a very comprehensive work. It contains factual and supportive information that can help to make life simpler, richer, and more rewarding to disabled people, their families, and friends. In one volume, it answers an amazing number of questions.

The *Source Book for the Disabled*, edited by Glorya Hale, is available from Paddington Press, 95 Madison Avenue, New York, NY 10016. 1979; 288 pages; 600 illustrations; $9.95 softback, $15.95 hardback.

—Larry Volin

Mr. Volin is on the staff of the State Relations Division of the President's Committee.

RSVP

Deaf Awareness . . .

Thanks for sending the copies of "In California, Social Reform Starts at Home" (Vol. 2, No. 6). Pam Hoye sure did a terrific job! The interesting thing is how much she learned about deafness in the process. Quite a lady!

Glenn A. Goldberg, Executive Director
Deaf Counseling, Advocacy and Referral Agency
Oakland, CA

President's Committee . . .

The inside cover states that "Disabled USA" "presents the case for disabled adults." However, the (Vol. 2, No. 7) issue defends the action of United Cerebral Palsy and other "poster children" organizations by saying they are trying to do better; makes a real case for sheltered shops (even though you are not "pro-workshop"); and accuses handicapped people of not caring enough to follow up on the White House Conference on Handicapped Individuals.

If all this presents "the case for disabled adults," I would not like to see the one against us. Many of us (disabled adults) have been busy fighting for our civil rights, for equal employment, for accessible transportation and housing. If memory serves me correctly, all these things were a part of the White House Conference.

Where is and where has PCEH been during the writing of the Department of Transportation Section 504 regulations, the battle for rehabilitation funding, etc? What has PCEH done to follow up on the White House Conference? I find nothing in "Disabled USA" to answer any of these questions.

What I find is that organizations for the handicapped are not such bad places after all, and I do not believe handicapped people need that kind of "case" made for them. We've been told that long enough! And handicapped persons who are currently fighting for their very lives against weak Section 504 regulations and an adverse Supreme Court decision, are told by an organization that takes no stands that we don't care about what happens to us. I find this all disgusting.

Karla M. Lortz
Delaware, OH

Ed Note: *Is it possible that disabled people want to hear only good about themselves, and only bad about others? "Disabled USA" offers criticism when it seems justified—and does the same with praise. This criticism and praise is offered equally to any organization, or individual, regardless of disability. Also, calling attention to PCEH activities is not the purpose of this magazine—PCEH activities are noted in other Committee newsletters dealing with specific need areas.*

Africa's Disabled Millions . . .

In Robert Ruffner's "Africa's Disabled Millions" (Vol. 2, No. 8), he notes that he visited seven West African nations and observed very limited treatment facilities available for handicapped persons. Had Mr. Ruffner visited Yaounde, the capitol city of Cameroon, he could have seen an impressive hospital-school for handicapped children.

Situated attractively on a kind of hilltop plateau, the main, one-story structure is extensive; it surrounds a courtyard in which there is a swimming pool. Supplementary buildings complete the establishment. In addition to exercise and treatment facilities, there are classrooms as well as dormitory rooms for live-in patients. Though this establishment cannot begin to assist the many handicapped in Cameroon, it is at least a splendid start.

. . . The hospital accepts patients from other African countries . . . on our recent visit to part of Cameroon, we observed that all Mr. Ruffner describes about handicapped people in other parts of Africa is there in Cameroon. Having seen the people before we toured the hospital for the handicapped, we were all the more impressed by the facility.

George Gleason
Southwest Missouri State University
Springfield, MO

Ed Note: *Mr. Ruffner wrote the article. However, he was describing a visit by James Burress, executive director of the People-To-People Committee.*

The Look of Sound . . .

Thank you very much for including reference to the Gallaudet College exhibit, "The Look of Sound," in "The Chairman's Column" of the Vol. 2, No. 9 issue of "Disabled USA". The exhibit, which was financed by generous gifts from corporations like IBM and many friends, has attracted thousands of people. We feel that it is a way to introduce the general public to, not only the problems of deafness, but the contributions which deaf people make to our society.

It is very important, however, that individuals know about the exhibit so that they will take a look.

Edward C. Merrill, Jr., President
Gallaudet College
Washington, DC

Ramada Inns . . .

I am concerned that perhaps a reprint under the title of the "The Chairman's Column" ("Welcome to Ramada Inn," Vol. 2, No. 9) was presented without investigation as to truthfulness.

A glowing exception is to be found here in Jefferson City, Missouri, our State capitol, where the Ramada Inn is *not* accessible and efforts to correct the situation are met with double talk—"yes, we will," but *no they don't.* That has been going on for years; it is obvious the

corporate level leadership is not committed to accessibility for all their facilities.

The "Chairman" should not lend his name to what can be interpreted as an endorsement of a business, which, in my opinion and experience, has not been responsive to the requests of the local and State Committees on the Employment of the Handicapped.

John M. "Jack" Keane, Director
Dept. of Labor & Industrial Relations
Jefferson City, MO

Ed Note: *Perhaps it is not the overall policy which falls short, but this particular facility.*

Parking Places . . .

The problem described in "Parking Places: A New Battlefield" (Vol. 2, No. 9) is widespread. Education of non-disabled drivers is needed. However, the one-to-one approach practiced by the author is too limited. May I suggest an easier and more far-reaching method.

As a member of the Westchester Coordinating Council for the Disabled, I accepted the assignment for a public relations campaign. All radio stations in the New York City area and Westchester, whose news desks I called, willingly cooperated. They requested public service spots in 10-, 15-, 30-, and 60-second lengths. Some wanted scripts, other tapes. In Westchester, I taped spots, identifying myself; city spots were anonymous.

All stations have aired the spots frequently for the past two months. People have mentioned that they have heard them on various stations. The spots seemed to have been welcomed as a popular public service announcement.

I shall be happy to send your readers a set of exactly timed and professionally prepared scripts of the various lengths. Your readers may submit them to their local radio stations, after preparatory calls to the news or public service managers, listing themselves as the resource persons.

It's that easy. I claim no copyright, just hope that many readers will avail themselves of the offer.

Lilly Bruck
In Touch Networks, Inc.
322 West 48th Street
New York, NY 10036, (202)586-5588.

Ed Note: *What a generous offer! In requesting scripts, please indicate whether you want the 10-, 15-, 30-, or 60-second length.*

Organizations of the Disabled . . .

Congratulations on your excellent and timely article, "Organizations of the Disabled: Has the Solution Become the Problem?" (Vol. 2, No. 10). Your critique should stimulate such organizations into making necessary course corrections before they lose many of the good people they need to achieve their goals.

While we do require continuity of purpose and direction, organizations tend to become stagnant and ineffective when the policy makers isolate themselves from the constituents and listen only to each other.

Apathy and indifference among the rank and file will occur if the "power structure" is the source of all knowledge and believes only they are capable of doing the right things. I don't think the majority of the disabled wish to trade the professional rehabilitation hierarchy for one of the professional handicapped.

Disagreement can be a very good thing when used in a constructive manner. There is no one right way to the resolution of our complex problems. Strategy and tactics which are perfected in an atmosphere of give-and-take are more likely to approach the ideal than when they are developed by a group where conformity is dominant. Further, those closely involved may overlook many important things which can be readily observed from a distance.

Leaders need prodding and criticism on occasion, if only to force them to review their actions and options. I hope you will continue to function as a critic of organizations of the disabled. We have reached a point in our maturity where we should be able to accept the fact that we can be wrong and we don't really have all the answers yet. Write on!

John J. Gavin, President
Foundation for Science and the Handicapped
26827 Sturdy Oak Drive
Elkhart, IN 46514

Breaking the Sound Barrier . . .

I just wanted to tell you how much I enjoyed the article, "Kitty O'Neil: Breaking the Sound Barrier" (Vol. 2, No. 10). It meant a lot to my family, because we are the parents of a 15-year-old deaf girl. Her name is Maria.

Maria is an AAU swimmer. She is on the Auburn City team and swims in lots of meets. (Not nationals yet, but she has dreamed of getting there. Her dream is to go to the Olympics.)

Maria has attended public schools from the first grade and also depends on lip reading for her help. She is a very determined girl who has a lot of guts. She reminds me of Kitty O'Neil.

Mrs. Charles E. Lindsey
East Tallassee, AL

United Cerebral Palsy . . .

I very much appreciate the fact that you have taken the time to look into some of the things we are doing in UCP and to comment favorably about those you think are helping to change the image of persons with disabilities. ("United Cerebral Palsy: Communicating a Better Image," Vol. 2, No. 7.)

Be assured that we will continue to work in this direction. Knowing that we have in you a built-in evaluator will

undoubtedly make us even more sensitive as we develop new materials and new approaches.

Earl H. Cunerd
Executive Director
United Cerebral Palsy Assoc., Inc.
New York, NY

It takes a pretty big person to do an even *partial* about face on a strongly held viewpoint. But that is what you have done in your article on UCP

You zinged us where you still felt we had it coming, but, on the other hand, you went out of your way to be eminently fair and even graciously complimentary in areas where you felt we were deserving of praise.

I, for one, appreciate it very much and will continue to value your appraisals on everything we do.

George V. McNally
Director, Radio-TV
Public Relations
UCPA, Inc.
New York, NY

We in San Antonio are trying to follow the basic concepts of UCP which you have so capably outlined. We serve, at this time, only adults with cerebral palsy or related disorders. Our total caseload is made up of adults who have been rejected by all other vocational programs.

So, without exploitation or "making a profit" on our sheltered workshop or letting industry use our people's services at slave rates . . . . we are mighty proud of the accomplishments our people have made.

Most of our participants came out of State schools, hospitals or nursing homes and are now living (semi-independently) in apartments . . . . two or three residents per unit with a homemaker. Adults who never knew until their food was on the plate what they were going to have for dinner, now plan, budget, purchase, and are involved in the cooking of their meals. No one is helped to do anything they are capable of doing themselves . . . . even though these capabilities were hidden even from themselves.

The "Mini-Housing" program, as we call it, has 20 persons living semi-independently (with one graduate to total independent living). With financial support coming from SSI, HUD Section 8 rent subsidy, and homemakers provided under Title XX by the Texas Department of Human Resources, the total cost to the taxpayer is about $100,000 for the 20 residents. The same 20 living (if you call it really living) in a State institution costs the taxpayer . . . $450,000 per year.

Robert Mazer, Executive Director
United Cerebral Palsy Assoc., Inc.
2336 Jackson Keller Road
San Antonio, TX 78230

The latest issue of "Disabled USA" arrived today and as usual, I enjoyed it very much. I was particularly interested in your story about UCP and couldn't agree more with your comments about the Telethon.

I was sort of roped into one of these a couple of years ago, when the local station made a couple of segments dealing with an expanded keyboard typewriter, foot operated, and a six panel communication board which I had made for a couple of Rhode Island CP's. After the Telethon was over, I wrote a letter about it to one of the UCP people . . . I am sure that all of the cheap nightclub acts and the weepy "fading stars" did a lot more harm than good, and so was delighted to read your comments.

Walter C. Hadley
Newport, RI

How Nice . . .

Thank you for sending me several past copies of "Disabled USA."

Since you are the bell-wether for most of the advances that are being made, it is important to read about what the future may hold.

Lyle Pringle
Coordinator for the Handicapped
Etobicoke, Ontario, Canada

"Disabled USA" came today.

It did not take long to realize a beautiful transformation had taken place. The stiff, uncertain, over-zealous statements of a "novice convert" had been softened and made to flow at an editor's certain hand.

Thank you for seeing the thoughts I had tried to express, and encouraging their development. I am hoping that some of my zeal will lessen with time and experience. As my most recent letter suggests, there is still much about deaf awareness I have yet to learn and begin to understand.

I feel somewhat as if I should be sharing credit with the editor for this particular article. Although this credit is not in print, I will always be appreciative of the editor's creative touch.

Pam Hoye
San Diego, CA

Ed. Note: *Hoye's article, "In California, Social Reform Starts at Home," (Vol. 2, No. 6) was a well-written story in and of itself. However, the editor's "creative touch" she credits comes from the "certain hand" of Muriel Horton-Strassler, our associate editor.*

We tend to become too enmeshed in the daily hassle and sometimes forget to say "Thank You."

There is no immediate incentive for this other than a realization that I have "intended to" (for so long it is embarrassing) say thanks for making "Disabled USA" the continually interesting and informative publication it is.

Edward C. Carney
Director, Public Information
National Association of the Deaf
Silver Spring, MD

The Chairman's Column

FREE CALENDARS ... The "Fourth Annual Great Calendar Give-away" is now going strong, according to the San Francisco Lighthouse for the Blind. Large print calendars are collected from the Zellerbach Paper Company, Union Paper Company, and other businesses. Braille Calendars come from the Braille Institute and the American Brotherhood of the Blind. All are distributed free of charge. To get a large print or braille calendar, contact: The San Francisco Lighthouse for the Blind, Inc., 1155 Mission Street, San Francisco, CA 94103. (415) 431-1481.

NEW CONSUMERS GROUP ... A new Consumers Organization for the Hearing Impaired has just been created as a national voice for hard-of-hearing persons across the country. Dr. George W. Fellendorf was elected president. One of the objectives: Elimination of misunderstanding about hard-of-hearing workers and job seekers Membership brochures are available from Margaret Danowski, Consumers Organization for the Hearing Impaired, Box 166, Owings Mills, MD 21117.

NEW BOOK ... The proceedings of a symposium held in October 1978, at the University of Baltimore, has been edited for publication by George M. McDevitt, Project Director. Titled "The Handicapped Experience: Some Humanistic Perspectives," it explores the question of the image of the handicapped in history and literature; the philosophy behind mainstreaming; and the matter of legislating values. Special features include an unusual experience in "desensitizing," ranging from Hal Krentz and Lily Tomlin, to a special improvisational dramatic presentation by Baltimore's Theatre Project. Copies are available from: The Dean of Students, University of Baltimore, Charles Street at Mt. Royal Avenue, Baltimore, MD 21201. Price: $4.00.

SELF-CARE MANUAL ... Through a grant from the McDonald's Corporation, the National Spinal Cord Injury Foundation (formerly the National Paraplegia Foundation) has published an updated handbook of self-care for people with spinal cord injuries.

Called "Handbook of Care for Paraplegics and Quadriplegics," the booklet is available in both Spanish and English. It contains a glossary of terms and information on: Skin care; avoiding urinary tract infections; respiratory care at home; nutrition; equipment care, and more.

The booklet is particularly useful for the newly injured upon their return to community living. Copies are available at no charge by contacting: Publications, National Spinal Cord Injury Foundation, 369 Elliot Street, Newton Upper Falls, MA 02164. (617) 964-0521. Specify if you want the English or Spanish version.

UNIQUE OPPORTUNITY ... For schools, colleges, parent and community groups, museums, parks: Help is available this school year to assist in accommodating the needs of handicapped students in science classrooms and laboratories, and in science museums and nature study programs.

Dorothy Tombaugh, a science teacher, on leave from Euclid Senior High School, Euclid, Ohio, will travel across the country visiting interested groups to consult on science education of the handicapped.

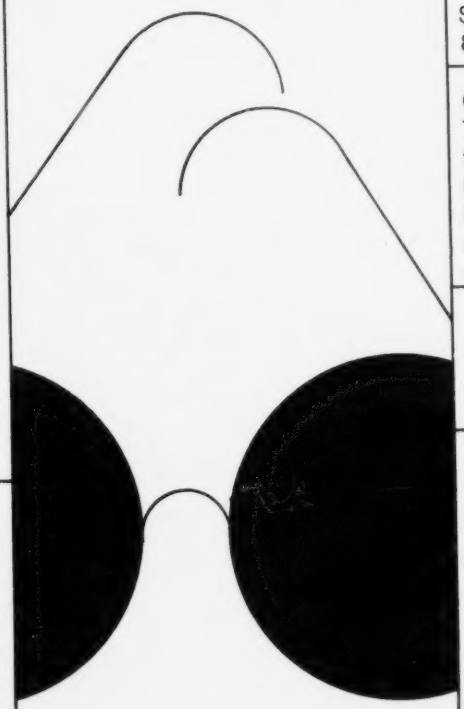
Mrs. Tombaugh is author of "Biology for the Blind," and numerous articles. She is noted nationwide for the successful strategies she has developed for integrating physically handicapped students with other students in biology, chemistry, and physical science classrooms and laboratories.

During this school year, her school system has granted her leave, and the National Science Foundation has awarded her a grant to allow her to devote herself full time to consult with groups across the nation. The American Association for the Advancement of Science, Project on the Handicapped in Science, endorses Tombaugh's project, and is assisting her in promotion and scheduling.

Groups interested in using Tombaugh's consultation, at no charge, should write or call: American Association for the Advancement of Science, Project on the Handicapped in Science, 1776 Massachusetts Avenue, N.W., Washington, DC 20036. (202) 467-4498 (Voice or TTY).

TEL AVIV NEWS ... The world's first "International Conference on the Medico-Legal Aspects of Disability" will take place in Tel Aviv, Israel, in November 1980. People of the legal and medical professions meeting together will take up such matters as the rights of disabled persons, the medical and legal criteria of disabilities, family problems of disabled people, and much more. For further information, write: The First International Convention On Medico-Legal Aspects of Disability, P.O. Box 3059, Tel Aviv, Israel.

SKI PROGRAM ... The Sixth Annual Ski for Light International Program will be held in Traverse City, Michigan, February 17-24, 1980. The program is designed to introduce visually impaired and other disabled people to cross-country skiing or ski touring. Paraplegics use specially designed sleds known as "pulks," and shortened ski poles. There will be training programs, informal races, and a demonstration program, as well as other activities and events.



Ski for Light is a one-to-one program, and blind and pulk skiers, as well as guides, come from throughout the United States and Canada, Norway and other countries. Ages of participants range from 18-80, and there are about an equal number of men and women.

Participants will stay at the Park Place Motor Inn, which has fully accessible rooms. Total cost is $200, which includes room, board and trail fees. Some travel grants are also available, according to need. For more information, write: Ski for Light, Inc., 1455 W. Lake Street, Minneapolis, MN 55408. (612) 827-3611.

OOPS ... OOPS ... OOPS! ... The TTY number for the Smithsonian's Office of Elementary and Secondary Education in Vol. 2, No. 10 of "Disabled USA" was *wrong*. The correct number to reach this office on TTY is (202) 381-4411.

Harold Russell

THE PRESIDENT'S COMMITTEE
ON EMPLOYMENT OF
THE HANDICAPPED
WASHINGTON, D.C.
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VOL. 3 NO. 4, 1980

DISABLEDUSA

Planning for the 80's: A "Disabled USA" survey . . .
The Unmet Needs of Disabled People . . .
Welcome to Winnipeg: The Coming World Congress

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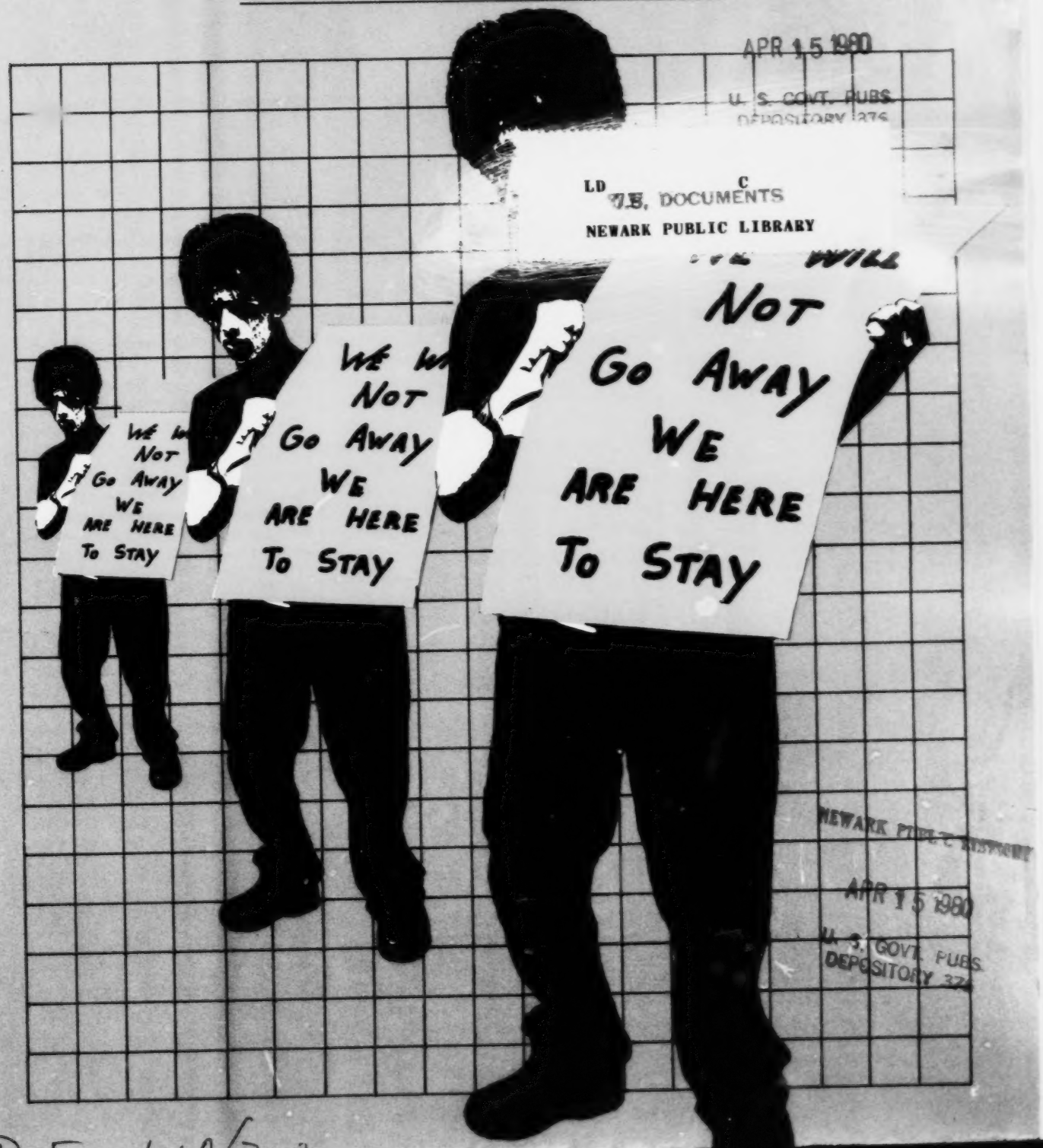

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DISABLEDUSA

VOL. 3 NO. 4, 1980

In this issue we focus on the 1980's, and what prominent people in many different fields think is needed to improve the lives of disabled Americans in the new decade.

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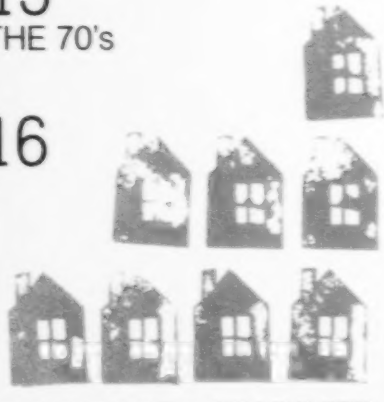

COMMUNITY OF UNMET NEEDS

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CHAIRMAN'S COLUMN

PHOTO CREDITS: All photos, U.S. Department of Labor

Harold Russell, Chairman

Bernard Posner, Executive Director

Vice Chairpersons:
Robert Sampson
Judy Heumann
Jane Baker Spain
Charles H. Pillard

Diane Lattin, Editor
Muriel Horton-Strassler, Associate Editor
Ron Shook, Program Assistant
Robert Lovelace, Art Director

DISABLED USA reports progress in opportunities for all handicapped workers, keeps Governors' and Community Committees informed of new ideas and activities, and provides all readers with general information concerning developments in rehabilitation and placement of people with disabilities. In a phrase, Disabled USA presents the case for disabled adults.

The Chairman of the President's Committee on Employment of the Handicapped has determined that the publication of this periodical is necessary in the transaction of the public business required by law of this Agency. Use of funds for printing this periodical has been approved by the Director of the Office of Management and Budget through August 15, 1981.

DISABLED USA encourages the submission of articles for publication by all readers, especially disabled people. Articles should be eight to ten, typewritten, doubled-spaced pages, written in an informal style. We also welcome letters from readers for the RSVP column. (All articles appearing in DISABLED USA may be reprinted with or without credit.)

THE PRESIDENT'S COMMITTEE ON EMPLOYMENT OF THE HANDICAPPED

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THE 1980'S

Philosophers make much use of two words which have special meaning to us as we leave the Decade of the Seventies and enter the Decade of the Eighties.

One of them is "being," the other is "becoming."

"Being" is a stage of existence we all try to reach. It is the goal, the ideal, we set for ourselves. "Becoming" is the pathway we take—often rocky and rutted—to try to get there.

For disabled people, "being" is indeed a modest goal. "Being" is a state of equality which non-handicapped people enjoy without even being aware of it.

It is a goal of being able to get places to learn things, to earn a decent living, to raise a family, to dare to dream and hope. If handicapped people insist on such things as transbuses with hydraulic lifts, and integrated education along with non-handicapped kids, and affirmative action in hiring, and accessible voting booths, it is not because they want to get an edge over non-handicapped people. Rather, it is because they want the *same* edge as non-handicapped people.

"Becoming," on the other hand, is our route to our goal. "Becoming" is not an end in itself, although some people act as though it were.

The Seventies has been a decade of "becoming" as has no other decade in American history. But it has been a particular kind of "becoming"—the "becoming" of creating blueprints and foundations.

There was the "becoming" of affirmative action and non-discrimination laws—Sections 501 and 503 and 504 of the Rehabilitation Act. There was the "becoming" of equal education for handicapped children in integrated classrooms.

There was the "becoming" of political awareness by handicapped people—the White House Conference on Handicapped Individuals; the growth of handicapped consumer organizations speaking out in their own behalf; the proliferation of laws and statutes at all governmental levels, all of these coming about because handicapped people were finding their political voices.

And there was the "becoming" of public awareness of handicapped people. No longer an invisible population, handicapped people are beginning to be noticed. Certainly, some backlash has accompanied this public notice—caused largely by public unfamiliarity with the goals of the handicapped population. But even this is preferable to sheer unawareness and neglect.

Looking back, the "becoming" of the Seventies has been one of creating beginnings, of digging foundations, of erecting signposts for the future.

Sections 501, 502 and 503 are just beginning their impact. So is the Education for All Handicapped Children Act. So are all the other laws of the Seventies. So is the handicapped consumers movement.

Now we step into the Eighties, and it would make such a neat package to be able to predict that the new decade will be one of "being," of reaching our goals.

But this is not to be.

Rather, the decade promises to be one of a different kind of "becoming"—a "becoming" not of creating new programs, but of making existing programs work; not of creating an affirmative action law, but of enforcing it; not of creating a concept of integrated education, but of implementing it.

Also, it will be a decade requiring our constant vigilance.

First, it always is more exciting and more breathtaking to create new programs than it is to bolster existing ones. This will be the decade to bolster existing programs; can we keep our excitement running high?

And second, there will be public resistance in the Eighties. We have seen it emerge in the latter part of the Seventies—resistance to the so-called costs of "reasonable accomodation" and to the costs of public transportation; resistance to affirmative action particularly when it applies to more severely handicapped people; resistance to handicapped children in regular classrooms; resistance to group homes for handicapped people moving into residential neighborhoods.

In short, it will probably be a decade not of the handicapped movement coming of age (it did that in the Seventies), but rather of the handicapped movement coming into maturity.

Maturity isn't all sunlight and roses. It's moving into your rightful place, settling in, living each day, solving each problem. It's "making it."

So the Decade of the Eighties will be one of the "becoming," of "making it," of reinforcing prior victories; of erecting the superstructure on the foundation we've created.

All the people whose comments follow have thought much about this new kind of "becoming." Their words, taken together, can be our banner to the new decade.

And please, save for the last the words of one of the writers who has summed things up eloquently; that way, his words will reverberate long in your mind. That writer is our President, Jimmy Carter.

Brave new Decade, we hail thee.

—Bernard Posner

Mr. Posner is executive director of the President's Committee.

PLANNING FOR THE 80'S

Progress and programs for people with disabilites during the 1980's will not just happen. They must be planned, discussed and supported. "Disabled USA" queried prominent people about their ideas and thoughts on the prospects for disabled people during the 1980's. Following are responses from leaders from many sectors of our society. Their thoughtful responses are worth serious consideration. In many ways they constitute a blueprint for disabled people during the decade ahead. These leaders responded to the following question sent to them by "Disabled USA".

"What is the one single new program or activity you would like to see come into existence in the 1980's to improve life for handicapped people?"

EMPLOYMENT OPPORTUNITIES

America must do more for its handicapped citizens. One of their most pressing needs is jobs. When given the opportunity to work, physically and mentally handicapped men and women show how useful and productive they can be.

Hiring the handicapped has acquired a new dimension under recently-enacted laws. Last year's Humphrey-Hawkins Full Employment and Balanced Growth Act commits the Nation to achieving full employment—actually four percent unemployment—by 1983.

One of [illegible] employment is to [illegible] opportunities for the handicapped, and other groups of Americans we have left out in the past in filling our needs for labor. At the same time, in order to fulfill the spirit of Humphrey-Hawkins, we must see that the handicapped and other groups of disadvantaged Americans receive every chance to take their rightful places in the labor market—receiving the jobs for which they are qualified, and having the opportunities they deserve to move up the promotional ladder.

Requirements to hire and promote the handicapped are written into law, but these laws do not cover all employers. The Rehabilitation Act of 1973, for example, requires the federal government and its contractors to provide equal opportunites to the handicapped. The same law requires the same of State and local governments, and other operators of employment and training programs which use federal funds.

When federal contract compliance programs in different federal agencies were consolidated into the Labor Department last year, we put more teeth into the requirement that government contractors take affirmative action to hire and promote the handicapped, and the handicapped victims of discrimination were given full-scale compliance reviews.

While government should set the example, we can only point the way. Four out of every five jobs in our economy are in private employment. Private employers, therefore, must carry the greatest share in providing opportunities for handicapped workers. Under the Targeted Jobs Tax Credit Program, employers in private industry have the opportunity to meet this obligation, and to receive a tax credit for doing so.

Because the handicapped are one of seven targeted groups under this innovative program, employers can fulfill a moral obligation and reap a financial reward at the same time.

The Labor Department has long offered funds for the training of handicapped workers, and special services are provided through the federal-State employment service, or Job Service. Sheltered workshops create opportunites for many handicapped persons who would not otherwise be employed.

Today, however, as we work toward full employment, we must be sure that what we are offering is full opportunity—not only to the handicapped, but to the other groups of Americans who have been the victims of chronic unemployment or under-employment. We must try harder to understand the unique problems of these men and women and to devise ways to make use of their talents more effectively.

This important objective goes far beyond helping the members of a specific minority group in our population. If we discriminate against any group of workers, or potential workers, on any ground other than ability to do a good job, all of society loses. We lose because we are not using our human resources fully, and because people are denied their right to be fully contributing and participating members of society. If we are to reach full employment, we must use fully the skills and talents of all our citizens.

For the handicapped, full opportunity in our democratic society is not just a legal requirement. It is something we should and must do.

Ray Marshall
Secretary of Labor

While we consider it very important to modify buildings, facilities, and work methods so that the physically and mentally handicapped can be employed, we recognize that this is only the beginning of a successful effort. Follow-on action must be taken if we are to achieve the desired end result of increasing the hiring and advancement of handicapped people at all levels of responsibility.

Integral to this are such initiatives as appointment of college-trained handicapped persons to trainee positions in occupations in which the full performance level is at the higher levels; the use of an agency-wide handicapped program reporting system to better pinpoint areas needing improvement; the use of affirmative action plans as a base for judging program advancements; appointment of program coordinators at a sufficiently high level of responsibility in the organization to ensure sound program management; and use of program coordinators to review disability retirement applications to increase the number of alternative placements of persons unable to perform their current jobs.

The military departments and Defense agencies have been asked to make wider use of these initiatives, and others, so that handicapped employees can receive their share of the career development and advancement opportunities within the Department of Defense.

Carl W. Clewlow
Deputy Assistant Secretary of Defense

The Department of State strongly supports the employment, placement and promotion of handicapped individuals. We are now actively recruiting several handicapped individuals for Civil Service positions, and we expect to implement a program in the near future for employing handicapped individuals in the Foreign Service. In addition, we expect to complete extensive modifications to the Department of State building to make it more accessible to individuals with various handicaps, and we are now undergoing a survey to establish the need for similar modifications in our embassies and consulates overseas.

In addition to these relatively short-term Department of State objectives concerning access to buildings, and long-term objectives concerning individuals in the 1980's, I am pleased to note that the Department of State and the Department of Health, Education, and Welfare will co-chair an Inter-Agency Committee to prepare for the observance of 1981 as the International Year of Disabled Persons. I particularly hope that our participation in this significant event will result in a better life for disabled persons not only in the United States but throughout the world.

Cyrus Vance
Secretary of State

I do not have one single program or activity which I feel we should focus on in the 80's. Rather, my inclination is to address as many issues facing disabled individuals as possible with a strong emphasis on the problems of the *unemployed* disabled person.

The disabled, as a group, suffer a disproportionately high unemployment rate, and much more public education is needed on this particular unemployment problem. I would like to see the labor movement take a lead in working to develop jobs for the disabled population, and to guard against discrimination of the handicapped. The labor movement has not been involved enough in addressing the needs of the unemployed disabled and, hopefully, the decade of the 80's will bring a change in this pattern.

Jim Savarese
Director, Department of Public Policy Analysis
American Federation of State, County, and Municipal Employees

I believe my answer to the question concerning improved life for handicapped people would certainly have to be a program to create more jobs in our country.

Many handicapped people, as well as others, are capable and willing to work, but there are not enough jobs to go around.

Our handicapped citizens want what we all want—an opportunity to live independent, active and full

lives. Without a job, it is difficult to do this.

Glenn E. Watts,
President
Communication
Workers
of America

There have been many measures introduced in this Congress and previous ones which have addressed the issue I believe most important to every individual—meaningful employment. According to the 1970 census, there are approximately 12 million non-institutionalized persons aged 18 to 64 years who are disabled and handicapped. At least 7 million of these individuals can and are able to work.

The extent to which these capable individuals have been denied employment in their communities is alarming, and that is why earlier this year I introduced S. 591. This bill will amend title XVI of the Social Security Act with respect to presumptive disability, earned income in sheltered workshops, benefits for individuals who work despite a severe medical impairment, and the exclusion of certain work expenses in determining substantial gainful activity.

SSI provisions have been built on the misconception that handicapped persons do not and cannot work. We know now that this is simply not true. Handicapped citizens are making advances to be recognized as working individuals, not as statistics on the unemployment rolls.

In short, this bill would allow consideration of presumptive disability, income received in sheltered workshops to be deemed as earned income, allow persons who are disabled to continue to receive cash benefits even after their earnings reach the level of gainful activity, and the continuance of Medicaid benefits.

All disincentives that existed before should be eliminated and I will continue to work to accomplish this goal as a member of the Senate Finance Committee.

Bob Dole
United States Senator

At the present time there is perhaps no more formidable barrier to employment of disabled people than the existence of work disincentives in human service programs. Work disincentives are those features of these programs that exclude persons who overcome the handicaps caused by disability and go to work.

It is to me bitterly ironic that we force the very people we encourage to seek employment to choose between the services and economic assistance they need for their daily lives, and an earned income that often is insufficient to sustain the personal support systems upon which they depend.

Although the American people have a long history of generosity and charity toward persons in need, we never have moved away from the idea that, with effort and personal resolve, these same recipients can free themselves from need. We must recognize that many disabled Americans cannot maintain employment and independence without resources they, as individuals, cannot provide.

A disability that causes physical dependence does not preclude possession of knowledge, skills, and abilities that make an individual employable. Disabled people who are qualified for work and wish to find jobs must not be denied the support that can make gainful employment a reality.

The Equal Employment Opportunity Commission has targeted a group of severe disabilities for special emphasis in federal affirmative action programs during fiscal year 1980. I am seriously concerned that our efforts will be blunted by a system of human services that forces qualified people to remain idle against their wishes, in spite of the clear capacity to work.

In sum, very early in the 1980's I would like to see a program or set of programs developed to meet the specific continuing needs of severely disabled persons who are employed or are able to be employed. Until this happens, true equal employment opportunity will remain an illusion for many disabled Americans.

Eleanor Holmes Norton, Chair
Equal Employment Opportunity Commission

INDEPENDENT LIVING

My hope is that most people are saying to you that the single most important issue and opportunity that faces all of us who should be dedicated to improving the life of the handicapped would be the adequate funding and development of the independent living legislation. I personally hope that we can establish an entitlement to independent living programs and services that would be based on the demonstration of need and the right to live life with full human dignity, and not surrounded by a lot of other qualifying terms.

John F. Larberg
National Director of Community and Patient Services
National Multiple Sclerosis Society

The growth of the independent living movement in California over the past 10 years has clearly demonstrated the tremendous importance of the State's In-Home Supportive Services (IHSS) program. This program has been the single most important factor determining the ability of an individual with a severe disability to move from a situation of dependency to social and economic independence.

Without such a program on the national level, the new Title VII of the Rehabilitation Act Amendments will not be able to achieve its promise. How can rehabilitation agencies help people toward greater independence if this country does not have a services system that enables people to maintain that level of independence?

Edward V. Roberts, Director
California Department of Rehabilitation

ELIMINATING BARRIERS

I believe that America's handicapped citizens have a right to greater accessibility to the nation's transportation system in the 1980's. To help achieve this objective, the Department of Transportation has issued a regulation implementing Section 504 of the Rehabilitation Act of 1973, which will assure that federally financed transportation systems are made accessible to handicapped persons.

As Secretary of Transportation, I intend to ensure that this regulation is effectively implemented. The changes brought about by our regulation should help disabled persons to move about in society in a manner that is dignified, and which permits them to reach their maximum level of capability.

In the 1980's we should also see advances in the design and technology of buses, trains, aircraft and mass transit vehicles to make travel for disabled Americans comfortable and convenient. I believe government and industry must continue to use their vast resources to work for the achievement of this goal.

Neil Goldschmidt
Secretary of Transportation

I would like to see a government-sponsored program in which students studying to be architects would learn about barrier-free design.

Most architects today do not learn about this problem from the "ground-floor," but only after they've reached the "penthouse" via the stairs! Unless an architect is made aware of the problem of accessibility, even today, this architect will design buildings that may not necessarily be accessible, or if they are accessible, it is likely to be back-door accessibility.

Such a program would be of immeasurable importance, and I would hope it would last from six months to a year and be a *required* course for all architects and all schools of architecture.

Itzhak Perlman
Concert Violinist

We hope in the coming decade to increase HUD's efforts to assure that the disabled are appropriately represented and addressed throughout all of the Department's programs and activities.

The provision of housing and related facilities that meet the special needs of the handicapped person's desire for independent living is a goal with which HUD is in full accord.

We have taken a number of steps to remove barriers that prevent the handicapped from participating fully in activities.

We have created an Office of Independent Living for the Disabled to promote and oversee program steps that are taken; to make sure that the interests of disabled persons are considered in policy-making decisions; and to examine ways HUD and other federal agencies can produce a better living and working environment.

We have stipulated that five percent of the family housing constructed under the Public Housing and Section 8 programs be barrier free. Also, we urge communities that qualify under the Community Development Block Grant program to spend a larger proportion of their funds to eliminate architectural barriers and to acquire, build, or substantially rehabilitate facilities as training and recreational centers for disabled persons.

In September, we announced reservation of $99 million for over 3,000 housing units to be provided for the disabled. Of this amount, $25 million was set aside for a demonstration program to increase housing and services available to mentally ill individuals. The Department of Health, Education and Welfare is collaborating on this program.

With congregate services authorized by the Housing and Community Development Amendments of 1978, we have begun to implement projects for the delivery of meals, personal assistance, and chore services to disabled residents in subsidized housing.

We are initiating a new technical assistance program to heighten awareness of the problems encountered

in housing disabled individuals and to develop model approaches to solve them.

In summary, in the 1980's we will be striving to enhance HUD's leadership in development of community housing for the disabled population.

Moon Landrieu
Secretary of Housing and Urban Development

The simplest things are often the most difficult. Americans who are not handicapped cannot comprehend how blessed they are in simply being able to leave their homes and go to work. This mobility, and the dignity that comes with it, is what I would wish for America's handicapped, but I am not under the illusion that wishing will make it so.

Transporting the handicapped, aside from the lucky few who can drive their own specially-adapted cars, requires the utmost imagination and innovation. Special equipment, such as buses that permit passengers in wheelchairs to board unaided, has been tested in a few cities. It shows promise but clearly no single device or system will do the job. It is a many-sided problem and many solutions will be needed. The important thing is that hundreds of thousands of potentially productive workers are rusting at home. They want to go to *work*, and we will all benefit if ways can be found to get them there.

Juanita M. Kreps
Secretary of Commerce

CHANGING ATTITUDES

Optimistically, I would like to see the 1980's as a period of inclusion of the needs of handicapped persons in the general design and development of our society. The general specifications for buildings, programs and services take into consideration a variety of sizes, interests and needs of people.

Handicapped Americans need to be considered in these normal array of needs and interests that comprise the general community. Approaching the inclusion of handicapped citizens from the perspective that they represent normal individual variations of any large group of general citizens that contribute to the strength of society by its rich diversity, will provide a positive framework from which America can build strongly in all areas of life.

We need to pursue and promote this concept of normalcy as opposed to the special programming or needs of the handicapped philosophy. Six feet tall Americans of today would feel very handicapped in the much shorter beds manufactured before the 1930's. The unique needs of tall people are no more or less unique than some of the needs of persons with disability. The challenge of the 1980's is to develop this new frame of reference. We can do it if we who have a disability believe it ourselves, first.

Albert T. Pimentel,
Executive Director
National Association of the Deaf

While not a new program or activity I would like to see the re-emphasis by all Americans to strive to remove the barriers of the mind that prevent so many useful and talented human beings from finding a position in the labor market.

Hopefully with labor, management and groups like the President's Committee on Employment of the Handicapped, we will make significant inroads to this goal in the 1980's.

Charles H. Pillard,
International President
International Brotherhood of Electrical Workers

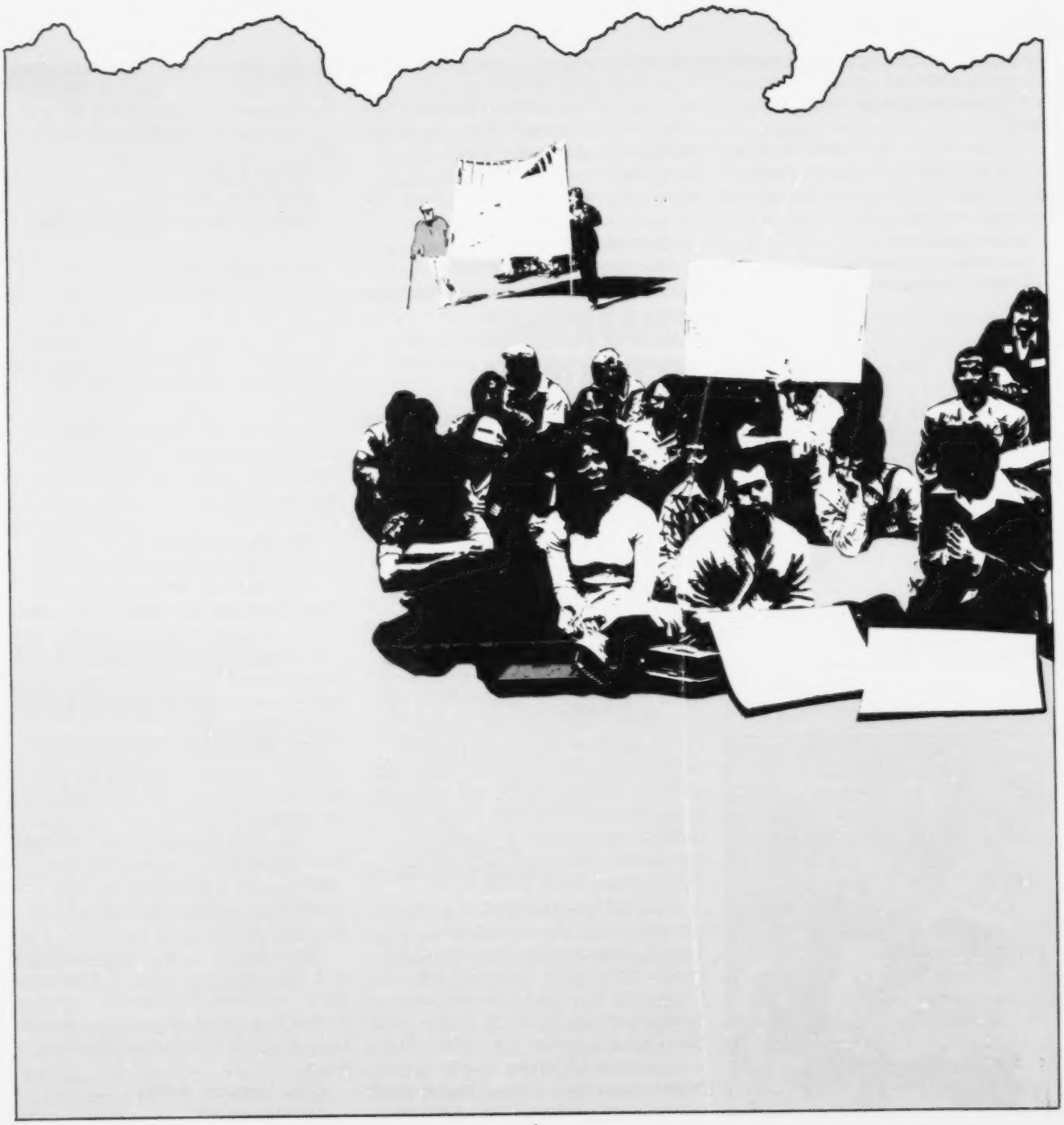
A publication asked me a somewhat similar question in 1940 (what insurance laws would benefit the handicapped), and I answered:

"I do not think laws are important. It all depends on what advantage we take of our opportunities and what opportunities we make for ourselves."

In the past 40 years I have not seen anything, nor do I expect to in the 1980's, to be a substitute for individual motivation, initiative, guts, or whatever you want to call it.

There are more opportunities today, and they shall continue to increase in the years ahead. But there is, and shall continue to be, a tremendous need for personal motivation to take advantage of them.

C. J. Lampos, Editor
"Achievement"



The single most important need which handicapped persons have is for a more comprehensive and thorough understanding of the disabled person in society. I need not substantiate this with many incidents, some humorous and some tragic, which indicate the limited awareness and understanding of the general public of the potential, the rights, and the contributions of handicapped Americans.

If this is the most central need, then the program or activity which I would like to see come into existence in the 1980's is a comprehensive effort on the part of most organizations and agencies in the United States to develop an awareness and deep understanding of the handicapped American.

Such a program or service would not be superficial, but would require the actual involvement of vast numbers of persons with handicapped people. Not only would this be a tremendously humbling experience for most persons, but through involvement would come awareness, from awareness would come the desire for understanding, and from understanding would come acceptance.

Once handicapped people have been accepted as citizens who are not different from any other person except that they have a greater challenge in life, we would see our handicapped friends move into a new world which holds them in high respect, and which offers the dignity which they rightly deserve.

Edward C. Merrill, Jr.
President, Gallaudet College

The message that keeps coming through to me from "Accent" readers is that their greatest "disability" is what able-bodied people *think they can't do!* I think this negative attitude reaches into all areas of one's life. I think it is time for all organizations providing services for those with disabilities, including all organizations of disabled people, to join forces in an "image building program."

The President's Committee could take the lead by calling together leaders of all these organizations into what would be a most important planning workshop, where specific ideas and procedures would be the result. This could be a "Blueprint for Action" that could be used by all participating organizations, as well as be disseminated to all those who were not able to participate in the planning. I see this as a public relations-type thing and the more organizations that participate, then the more effective this program could become.

Raymond C. Cheever
Publisher and Editor
"Accent on Living"

In my opinion, in the 1980's we must stress efforts to eliminate attitudinal barriers which are detrimental to full and equal opportunity for handicapped persons. Although much progress has been made in this area in the last decade, even more remains to be done.

I believe that we must develop new and creative means of educating the American public to the vast untapped potential of the handicapped. A recent film, "A Different Approach," which we have used within Treasury, has been very well received, and promises to have a significant impact on attitudinal problems. If we can develop more of these attention-getting devices, we should see rapid progress made toward the goal of improving life for all citizens.

William Miller, Secretary
of the Treasury

During the coming decade, efforts need to be concentrated in two areas: Effectively changing the attitudes of the public, and enforcing disabled people's civil rights. Rather than opposing each other, these two goals are complementary. Researchers have found that the only truly effective way to change public attitudes about disabled people is to bring about natural daily interaction between disabled and non-disabled people as equals, as co-workers, co-students, etc.

The only fast and effective means to bring about this daily contact is to eliminate discriminatory practices and barriers that exclude disabled people from jobs, housing, education, transportation, recreation or other major activities.

We must convince the public, through constant contact with disabled people, that disabled people need not become basket cases, sent to nursing homes,institutions, or forever left in a sheltered workshop. This is the general impression of disabled people that leads to patronization and condescention.

This is the negative stereotype that was tacitly endorsed by the Supreme Court in the *Davis* decision. Unless political leaders and policy makers understand that disability does not equate total dependence and helplessness, they will never feel free to spend public funds to create and support programs that promote independence, skills development, and employment.

There are still far too many Americans who believe that we can no longer afford social programs for disabled people and also support them through social welfare programs for those who cannot take care of themselves. They see the social programs as nice and well-intentioned,

but not necessary. The prevailing view is that since we can't literally grow back a person's amputated limb, spinal cord, or restore a person's sight or hearing, there really isn't any use in doing anything except pay them welfare.

Until we are seen by others as able to break away from total dependence, they will not see the wisdom of creating services and programs that allow us to gain control of our own lives.

Debbie Kaplan
Lawyer

In the 1980's the need will be for vigorous, effective implementation of existing programs. All programs and activities must be focused on achieving full access for disabled people to the life of our society. This requires an unremitting emphasis on mainstreaming and independence.

To achieve the full participation of disabled people, major barriers must be eliminated—not only the physical barriers, but, most importantly, the pervasive attitudinal barriers which build the walls of discrimination. Every effort must be made to change attitudes and purge ignorance. If we succeed in this, physical barriers can be prevented and the existing ones will be removed.

Robert M. Johnson, Executive Director
Architectural and Transportation Barriers Compliance Board

INFORMATION GAPS

The possibilities for any new program or activity are enormous. There are so many different handicaps, and further differences within the same type of handicap, that what may significantly aid some people may do nothing for others.

In the past few years, legislation mandating equal opportunity for handicapped persons has been passed. It is vitally important that responsible officials do everything within their power to fully implement the requirements of the law during the 1980's.

It is also important that a communications network be set up to ensure that handicapped persons are made aware of their rights, the opportunities and services that are available to them, and assisted in obtaining such opportunities and services.

I would like to see a program developed to implement an "Office of Special Services for the Handicapped" in every government agency. Each office could provide a variety of needed services to handicapped employees, members of the general public who are disabled, and other interested persons. Such an office could provide one or more full-time interpreters for the hearing or speech impaired, readers for the blind, and information, education and counseling services. The office could also provide information on availability of services.

For example, the Department of Agriculture could provide counseling on the Food Stamp Program, home loans, and other services provided by this agency. I have only scraped the surface, but the list of services could be expanded as persons with various handicaps voice their needs. Furthermore, such offices could also be established at State and local levels.

Bob Bergland
Secretary of Agriculture

I would think that a program offering disabled children, youth, and adults concrete and specific information about rights and services available to them would be the single most important step we can take. During the decade now ending, vitally important rights and services have been mandated by law. These rights will mean little to people who are not aware of what these laws provide, who is eligible, what to do to benefit from these rights and services, how to appeal unfavorable rulings, and what to do when violations occur.

It is ACCD's finding that as many as 85 percent of disabled people in America today do not know enough about these rights and services to be able to take full advantage of them. For almost nine out of every ten, then, these rights—which would revolutionize their lives—might as well not exist.

From this kind of thorough acquaintance with the provisions of key laws would flow the implementation, compliance, and enforcement that must characterize the 80's if the laws enacted in the 70's are to achieve their purpose. From this kind of a program, too, people who become disabled would quickly learn of essential rights and services.

If Patrick Henry was right in observing that eternal vigilance is the price of liberty, this must be equally true of rights as well.

Frank G. Bowe, Director
American Coalition of Citizens with Disabilities

FOCUS ON TECHNOLOGY

In the employment of the disabled, we in business would do well in the 1980's

to give more attention to the unique abilities that disabled persons can bring to their jobs and less to the inconveniences of making any necessary accommodations for their employment. Such accommodations, after all, are intended principally to create a more efficient work environment in which the disabled can make their full contribution.

Like other members of society, the disabled are users of telecommunications products and services, although they have special needs in some respects. The Bell System is cooperating closely with regulatory and other governmental agencies to meet those needs and to make telecommunications services more widely available to the disabled.

Charles L. Brown
Chairman of the Board
American Telephone and Telegraph

That technology offers abundant possibilities for improving the ability of disabled persons to function effectively and productively is unquestionable.

Take, for instance, the possibilities electronic communications devices are opening up for persons with speech difficulties. Many of the problems disabled persons face with transportation and access to facilities might well yield to the development of such devices as stair-climbing wheelchairs and electronically controlled prosthetics. And vistas are almost limitless for the use of computers and adaptive equipment that make it possible for physically disabled persons to perform capably in employment, at school and at home.

Today we are seeing only the tip of the technological iceberg. Getting to the solid mass needs and deserves a nationwide program which every agency concerned with the handicapped—both public and private—can support with research, information and other resources. We have long talked about humanizing technology. The chance is here to do so by using technology to open up opportunities for disabled persons to live independently.

This is a challenge we cannot ignore in the decade ahead if we truly mean what we say about mainstreaming.

Earl H. Cunerd, Executive Director
United Cerebral Palsy Associations

EXPANDED PROGRAMS

In order for our dreams for handicapped people, which began in the 1960's and the 1970's, to become realities in the 1980's, it would be impossible to single out one program as being of primary importance. If I were to be granted one wish for the handicapped for the next decade, I would wish that the programs for handicapped individuals that were in their infancy in the 1960's, and were expanded and further developed in the 1970's, would come to full fruition in the 1980's.

Jennings Randolph
United States Senator

DISABLED VETERANS

The National Urban League has been involved only peripherally with the problems of the handicapped to date. However, with the problems of the 80's and an increased awareness of the need for specialization, I believe the unique talents of impaired people to utilize residual abilities will come to the fore.

In my experience, impaired individuals frequently compensate for their impairment by overdeveloping residual skills. When these skills coincide with the particular needs of the job market, the match makes such individuals ideal employees. In my opinion, therefore, any ideal program for the 80's would involve increasing the awareness of impaired people of their strengths in an open job market.

One of the programs operated by the National Urban League is a project designed to find employment for severely disabled Vietnam era veterans. As part of this program we have incorporated a counseling network system which provides a transitional community for these veterans to work towards job placement and towards more active participation in the larger community. If I had to recommend only one program or activity to improve the lives of handicapped people, I would

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recommend, then, the kind of operation which is embodied in that program: i.e., a Peer-Support Self-Help Network which brings job placement efforts into the context of a community of positive expectations.

This community incorporated in our Disabled Veterans Employment Program, joins people of different skills, experiences, and levels of success and provides them with: a) training and specific skills, b) a forum to practice these skills with each other, and, c)a supportive network of contacts along with the traditional training and employment services typical of such programs.

We have found that through this combination program (originally designed to provide for the readjustment needs of disabled Vietnam veterans), we have been able to deliver a comprehensive service which assists handicapped veterans to find productive employment, while helping them to function more successfully in society despite their handicaps.

Vernon E. Jordan, Jr., President
National Urban League

EDUCATIONAL OPPORTUNITIES

The Education for All Handicapped Children Act (Public Law 94-142) has made great strides in identifying, diagnosing, and providing handicapped children with an appropriate education in the least restrictive environment. Nearly four million handicapped children across the country are receiving better instruction in public schools than ever before because that federal law (PL 94-142) requires local school districts to develop individualized instruction programs and include handicapped students in everyday classroom activities.

Parents, more than ever before, are involved in making decisions about their children's schooling. Teachers and administrators are becoming increasingly supportive of the needs of individual students, and are learning to deal with the needs of handicapped students in regular classroom environments.

Most of this activity, however, has taken place at the elementary school level. Our job in the 1980's must be to continue the momentum which has begun so successfully, and carry it into the secondary schools across the nation.

Secondary schools must meet the challenge of continuing the progress sparked in the lower grades. Their responsibility will be to prepare handicapped youth for employment and help them master independent living skills. The federal government, I believe, must assist in providing useful vocational and academic training in order to carry out our ultimate mission—to prepare handicapped people where appropriate to reside with independence and dignity in their communities.

In order to reach that goal, it is imperative that secondary schools receive the cooperation and support of vocational, educational, and rehabilitative services currently available in the community. Secondary teachers and counselors must be aware of the special needs of handicapped students, and the federal government must provide the incentive to ensure that such teacher training is provided.

Perhaps equally important in the evolution of PL 94-142 will be the need for better coordination between government agencies which deal with the unique concerns and needs of handicapped Americans. If we are to be successful in these tasks, effectiveness, efficiency, and cooperation must be our bywords, because in the coming decade human services programs will be forced to draw from an ever-decreasing supply of federal funds.

The 1980's will be the time to close the gaps in existing programs and to eliminate conflicting policies which now inadvertently impede the efficiency of federal and State agencies. Only through concerted efforts will we be able to dedicate our best efforts to providing handicapped young people with the opportunities and the skills they will certainly need to live full and independent lives.

Harrison A. Williams, Jr.
United States Senator

DEVELOPING NATIONS

In our view, the most important single problem concerning the disabled people worldwide during the 1980's is the extension of basic rehabilitation services to the tens of millions of disabled persons in developing countries who presently do not receive the services they need in order to remain or become active and useful members of their society.

Accordingly, the international community should make a special effort within the framework of the forthcoming International Year of Disabled Persons—1981—to work out a plan of

technical assistance and cooperation for making such extension possible. For that purpose, the United Nations will convene, subject to the approval by the present thirty-fourth session of the General Assembly, in 1981, an international symposium of experts to consider this and related questions.

Evner Ergun
Assistant Director, Social Development Branch Centre for Social Development and Humanitarian Affairs
The United Nations

MENTAL HEALTH COVERAGE

The single most important activity on behalf of the handicapped in the 1980's must be to see that all programs initiated or supported by the federal government remove every trace of discrimination against those persons suffering from mental illness.

In that regard, perhaps the single federal program most needed is equitable coverage for mentally ill persons in any national health insurance legislation to be passed by the United States Congress.

The words of Mrs. Hilda Robbins, 1979 National Mental Health Association president, in introducing the Mental Health Association "Plan of Coverage for the Mentally Ill in National Health Insurance," address the issue most eloquently:

"The people of this nation are clearly moving to claim a right to treatment when ill, and a right to health if attainable.

"Those leaders who will construct this claim and guarantee this right must, in their vision, and wisdom, and compassion give solemn assurance to those citizens who suffer the pain, the anguish, and the despair of mental illness, that they too, will receive equitable and appropriate access to these rights and benefits. It is quite frequently impossible for either a practitioner or a patient to distinguish or diagnose precisely between physical illness and mental illness.

"Therefore, it is to be hoped that neither legislators nor insurers will assume this awesome and arbitrary role. The only honest, appropriate and humane approach is to acknowledge that the misery of mental illness is as tormenting and unbearable to the individual, and as destructive, debilitating, and costly to the nation, and as legitimate and treatable to the scientific community as any physical illness.

"It is just and right and fair and reasonable to expect equal consideration for mental illness with physical illness, regardless of financial considerations or past patterns of discrimination. Neither cost, nor fear, nor ignorance, nor precedent should be allowed to cheat 20 million citizens of their right to treatment for mental illness, and their claim to mental health."

Jack McAllister, Executive Director
Mental Health Association

The greatest breakthrough for handicapped people in the 1980's would be for those of us who are not handicapped to eliminate the physical, social, and psychological barriers which keep the disabled from reaching their full potential.

During the last decade, handicapped people have made great progress toward achieving the basic human rights they have sought for so long. For the first time in history, the handicapped have found a common voice, and they have raised it forcefully in pursuit of what society had denied them: The right to an equal education; the right to seek and gain employment; the right to be judged as an individual; the right to be heard in our political system; the right to travel and to have access to buildings without the additional impediment of built-in barriers; and even the right to communicate with one another.

There has been progress, but there is still much more to be done—by government, by business and labor, by our educators, by all who are not disabled, and by handicapped people themselves. The decade of the 1980's can be the time when we finally guarantee to *all* our handicapped people the kind of human and civil rights to which they are entitled.

The 1980's can also be a period for freeing disabled people as much as possible from the physical limitations that compound the problems brought about by discrimination. We don't have to expect miracles or hold out false hopes, but if we put our resources to work, the decade ahead can produce technological and medical advances which will give the handicapped far greater opportuinites to live as they would wish.

I hesitate to single out any one program or activity which would be most important. As President, I am concerned above all with making our government and our people aware of the whole range of needs in this area, and we must continue to do hundreds of things, large and small. But let me give one example.

Just in the past five years, scientific research has raised the possibility that substantial progress can be made in bringing about spinal cord regeneration. An idea that would have been rejected as hopeless at the beginning of this decade is now an exciting challenge.

A breakthrough would dramatically change the lives of 150,000 Americans who have been paralyzed by spinal cord injuries.

Our goal for the 1980's should be the same as for the 1970's: To give handicapped people the best possible chance for human rights and human dignity. This will mean continuing to break through the barriers and discrimination which stand in the way of those rights, and it will mean using the best of our minds, our skills and our resources to help handicapped people overcome their physical disabilities wherever possible.

Jimmy Carter
President of the United States

THE 1970'S: A DECADE OF PROMISE

In the 1960's, America became aware of the existence and needs of its disabled citizens. We began to realize that disabled people are capable individuals with myriad talents and contributions to make. With the help of friends and advocates, disabled people were projected into the public eye.

Through the 1970's, disabled people themselves began the momentum for what is now a phenomenal strength at both the political and legislative levels. We have witnessed the disabled community growing and learning, and becoming, all the while, increasingly sophisticated at advocating for themselves.

We have seen disability groups learn to suppress some of their immediate specific needs to lend their strength of numbers to powerful coalitions which work for the best interests of all.

We have learned some harsh lessons about political life, and seen some of our best leaders literally burn themselves out in the struggle for equal rights. But we have also rejoiced as others have come forward, willing to sacrifice much of themselves to assume the twin burdens of leadership and responsibility.

We have seen the passage of landmark legislation of great promise in the areas of jobs, independent living, education, and other significant areas. Legislation which will, eventually, ensure that Americans with disabilities can enjoy the full measure of American citizenship.

In many of the cities, towns, and villages of America we have watched as elected officials, workers and friends have joined us in implementing some of the accessibility mandated by Section 504, and rejoiced that more of us with disabilities are able to work, love, worship and play with our fellow Americans.

We have seen the private sector make tentative gestures towards us in outreach, recruitment, advertising, and, sometimes hiring. We see changes being made, slowly, surely.

We have seen the great federal bureaucracy, which usually takes many years to move, show a sensitivity and willingness to recognize the immediacy of the needs of disabled people, and wisdom in encouraging and fostering more and better kinds of independence in our lives.

We have made a good start, learning many lessons. The laws of the land, that ultimate measure, now recognize and sanction the principle that we are, indeed, entitled to the full rights of American citizenship.

We have made a good start, but there is yet much more to be done.

Statistics tell us that 85 percent of our disabled people have not yet been identified, reached, or made aware of the rights and benefits which are now theirs.

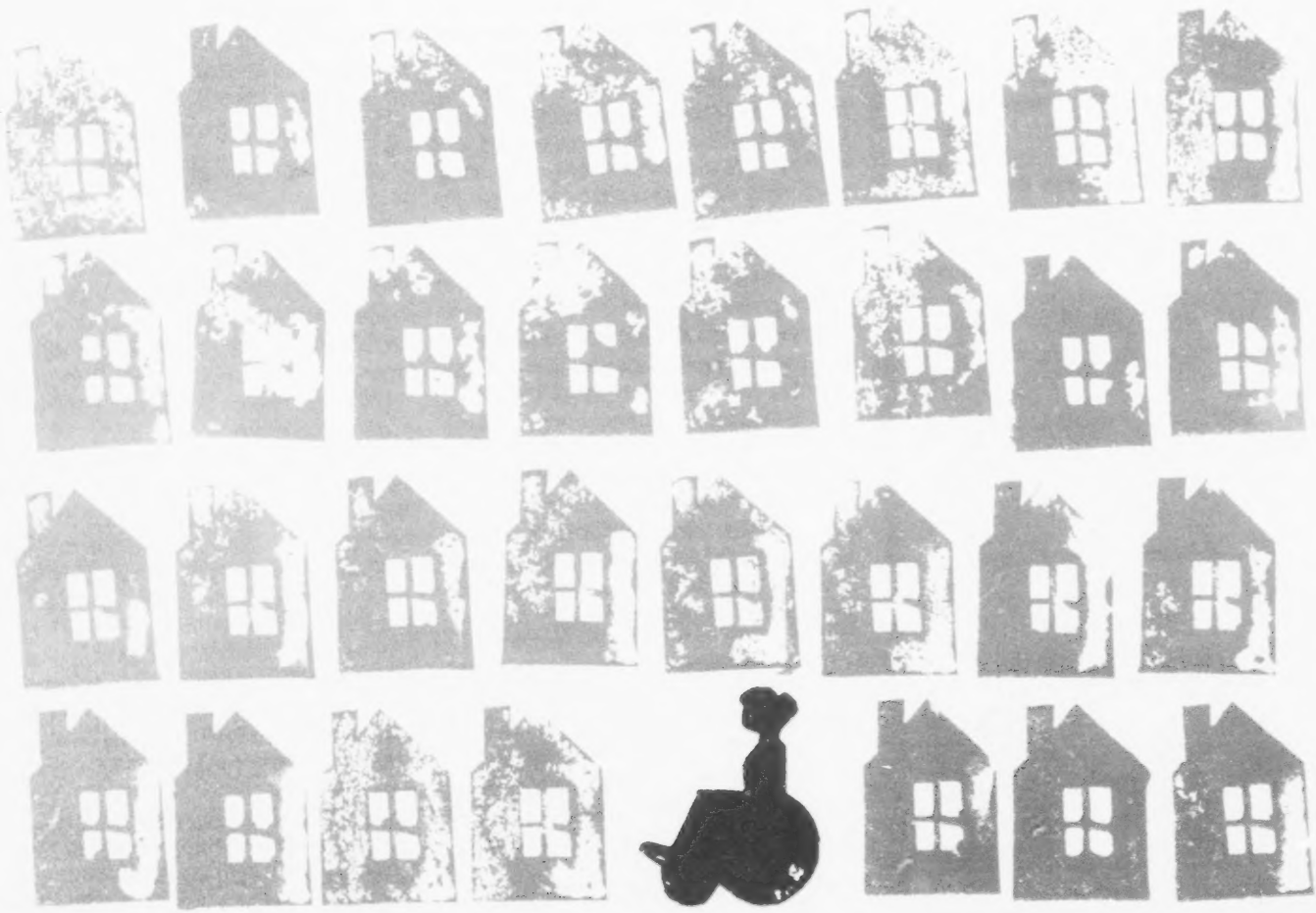
If these events and pieces of landmark legislation are to be truly meaningful, we must find and reach out to these large numbers of disabled people and show them, too, how to begin the struggle for implementation of these laws, and how to start the never-ending battle for funding to accomplish the intended results.

The 1970's have put these principles on paper.

The 1980's must put them to work. For all Americans.

—Muriel Horton-Strassler

Community of Unmet Needs



EMPLOYMENT

Many disabled persons do not work for reasons unrelated to employer attitudes and architectural barriers. Unavailability of support services, housing and transportation, as well as Social Security income limitations preventing part-time, transitional and self-employment, often prevent them from considering positions for which they may be qualified. None of these are the responsibility of employers, but they must be faced if handicapped persons are to enter the market for visible and responsible positions, which often require them to move to new communities.

Support Services: Employed disabled persons are often ineligible by reason of their income for personal and domestic services provided by public agencies, which are not otherwise available. Nor are agency personnel likely to be on duty at the hours when a handicapped employee needs them. Persons responding to private advertisements all too often lack the competence, reliability and discretion essential for these tasks. And in most communities there is no center where a disabled person moving in from out of town could go to learn about local resources, or to which an employer might refer him.

Housing: Most accessible housing is in federally-funded projects whose income limitations exclude many employed persons. When services such as shared attendants are provided primarily to residents of such housing, the employed are doubly excluded from help they may need to retain their jobs. Similar limitations exist in some disabled living centers.

Transportation: Existing vehicles which can transport wheelchairs are in constant use taking patients for treatment and therapy. Rates, when not covered by medical insurance, are far beyond the earnings of disabled employees. And the inability of such carriers to keep appointments for specific times makes it impossible to rely on them to get to work.

Social Security: Limitations on income for persons on total disability have not kept pace with increases in the minimum wage or with inflation. Persons whose level of earning before disability was above the minimum are prevented by almost immediate loss of all benefits from working their way into a new career in part-time or transitional employment. Nor, even if they could support themselves by self-employment, can they compromise their eligibility for Medicare, since there is no major medical insurance available to them otherwise.

These problems are clearly not the concern of employers, yet the obvious necessity of dealing with them may be one more reason why employers hesitate to consider disabled persons. Many agencies are prevented by regulations and policies, often not their own, from tackling them. Yet, as in so many other areas, the very fact that no one wants to get involved makes these issues far more difficult for the handicapped people who need them.

Any effort to clear the way for handicapped persons to work, as much as their limitations permit, would quickly pay for itself in their increased productivity and reduced dependence upon public assistance—to say nothing of the intangible benefits to themselves, and the community as a whole as a result of their equal participation in the world of work.

DISABILITY BENEFITS

The present income limitations for persons receiving Social Security disability benefits work an unintended hardship on disabled persons, because they have not kept pace with increases in the minimum wage or with inflation in the prices of food, fuel and medical services. Since these limits in practice prevent handicapped persons from earning any significant amounts, they must often either do without essentials of life or evade the rules. Revision of the regulations in accordance with their original intent could be done in the following ways:

Income Limits: When the minimum wage was $1.80/hr., the $181 limit permitted a disabled person to work 100 hours in a month, or somewhat more than half time. The $231 limit for termination of benefits permitted 156 hours of work, or nearly full-time employment. When the minimum wage reaches $3.10/hr., the handicapped individual can work only 54 hours without penalty, and only 90 hours without loss of all benefits. To restore the original intent of the regulations, these limits should be raised to at least $311 and $501.

Sliding Scale: The present limits may prevent persons whose level of earnings before disability was above the minimum wage from doing any significant work at all in the areas for which they are qualified. (This paradox is particularly conspicuous when they might serve as consultants on improving conditions for the handicapped, but must either refuse or donate services for which others are well paid!)

It would be fairer if the principle of dollar-for-dollar deductions for earnings received were extended upward to the total amount of their benefits, if they exceed $281. There should also be a "grace period"—say three months—during which persons who exceed the limit by self-employment may remain on the rolls without receiving any benefits.

Medicare: Disabled persons may be prevented from supporting themselves by self-employment because they thereby lose their eligibility for Medicare, and no other major medical coverage is available to them. The continuing non-hospital medical services which handicapped individuals may need to keep their jobs are often beyond their earnings—and indeed the means of anyone without insurance. It would be helpful if such persons, particularly those who are self-employed, could continue to participate in Medicare as subscribers by paying reasonable premiums based upon their level of income.

Such adjustments would rectify inequities which amount to discrimination against the employment of the handicapped by the very regulations intended to help them. Disabled persons would thus be permitted to work within their capacity, with less temptation to "moonlighting," which exposes them not only to possible prosecution for welfare fraud, but to blackmail from anyone who knows about it.

The government would find any additional administrative cost more than covered by savings from reduced benefits payments and investigative expense. Still more important for handicapped people would be the elimination of the demoralizing sense of being reduced to helplessness as much by the rules as by any physical limitation, and the pressing need to evade the regulations in order to survive.

ATTENDANTS

The proposed disabled living center attendant referral service will be par-

ticularly valuable to handicapped persons with no close relatives. It is indispensible that disabled persons secure attendants who are competent, reliable and discreet. But these days, people with these qualities usually prefer to work for institutions, which can offer higher salaries and fringe benefits, conventional working hours and conditions, and job security and advancement. Those available for private employment are often unable to secure other jobs. As a result, disabled persons may be prevented from considering suitable employment in unfamiliar communities, or even forced into residential institutions. A disabled living center could help in these ways:

Selection: Disabled individuals who advertise their needs lay themselves open to crank calls and imposition as well as plausible incompetents whom they may lack the knowledge to recognize. A staff member with several years service in the personnel office of a large hospital would have much experience interviewing the types of people likely to apply, as well as a wide acquaintance among licensed practical nurses and nurses' aides who might be able to recommend suitable applicants. And the applicants themselves might find it helpful to discuss the disabled person's needs with a third party from a responsible organization.

Supervision: Arrangements should have a formal structure, and an outside reference point to prevent imposition on both sides. A staff member could assist in preparing a written agreement stating the responsibilities of each party. There should also be periodic follow-up contacts with both, separately and together.

Handicapped persons can become very demanding, often without realizing it. And attendants inevitably become involved with another's physical well-being, property and private affairs can be tempted to carelessness, stealing or even blackmail if they believe themselves indispensible, irreplaceable, and unobserved. The disabled living center could also provide crisis referral service when problems arise which neither party knows how to handle.

Red Tape: Few handicapped persons know how to deal with employer obligations for tax withholding, Social Security, and State and local deductions. A staff member could keep up on these regulations, translate them into simple terms, and advise disabled employers. It might be more efficient for all concerned if this person simply handled the paper work.

These are very difficult problems, but they need to be tackled and the disabled living center need not do it alone. Further information could be sought as follows:

1) Compile a list of agencies and consumer organizations elsewhere concerned with this problem.

2) Correspond with these groups to find out what they are doing.

3) Invite the most promising contacts you develop to a conference or workshop. The conference could be used to attract wider attention, through local media coverage and by writing an article on it for an appropriate periodical.

COMMUNICATION

One of the most serious problems for handicapped persons is finding out what services are available when they need help. They may be further confused because many organizations are uncertain of the scope and limitations of their functions, which sometimes overlap and sometimes leave gaps between them. The disabled living center could do much by serving as a local and regional clearinghouse for information in such areas as these:

Directory: Community organizations as well as disabled individuals and their relatives and friends need to know what agencies serve handicapped persons in what ways. Some States include such information in county directories of human resource agencies.

Transportation: Groups wishing to transport members with limited mobility to community activities would sometimes like to borrow or lease wheelchair vans at times when their owners are not using them. The owners often have to refuse because they cannot supply qualified drivers or otherwise comply with various types of regulations. The center could maintain lists of such vehicles and of drivers, and inquire further into the regulations and means of complying with them.

Census: It would be helpful to many people in many ways to know how many people with what disabilities there are in the district, and where they live. "Operation Overcome" of the Lehigh Valley, a Pennsylvania organization, began such a census by having a brief locator form included with a local tax statement. Those who returned it were sent a questionnaire concerning their needs, and asking what resources were already available for meeting them.

The results were not utilized as fully as they might have been—for example, no report was published to draw attention to areas of need—but the method has great promise for increasing the efficiency of the disabled living center and other groups as well. Plotting residences of persons with various disabilities on a map would be particularly helpful in planning ways of sharing services.

These are, of course, only a beginning at bringing order out of the chaos of the handicpped world, but they would do something to lessen the confusion which often prevents disabled persons from dealing with problems while they are small and manageable. Many emergencies demanding great effort and expense arise precisely because help in ordinary, everyday situations which might prevent them, is not available or people do not know where to secure it.

The clearinghouse should therefore be conceived not merely as a crisis referral service for emergencies, but as a center for establishing communication concerning short-term and long-term needs of disabled persons and ways of meeting them. As such, it will not only provide a badly-needed service in its own community, but may well set an example for tackling a widespread problem elsewhere.

—Alice P. Kenney

NOTE: If you'd like to share your community's experiences with Ms. Kenney, please write: Alice P. Kenney, Project Director, *Museum Access*, 78 Salisbury Road, Delmar, NY 12054.

Come To Winnipeg

"Come, then, to Winnipeg with your hearts, with your expertise and your knowledge. Together, we will provide a dynamic impulse for change and for rectifying current inequities faced by disabled people."

These are the welcoming words of Patricia J. Harris, president of the 14th World Congress of Rehabilitation International, which will be held in Winnipeg, Canada, June 22 to 27, 1980. Hosted by the Canadian Rehabilitation Council for the Disabled (CRCD), the purpose of the Congress is to serve the interests of all concerned with disability, prevention and rehabilitation.

It will be the first World Congress to be held in Canada and the first in 20 years in North America. The theme of the 1980 Congress is "Prevention—Integration, Priorities for the 80's."

The 1980 Congress is being prepared with an eye to full and equal accommodation of all disabilities. Braille programs will be available in advance (upon request) from the Congress offices; interpreters for hearing impaired people will be provided; a "welcoming committee" will be at the Winnipeg Airport to serve the needs of Congress participants; and transportation will be accessible and will be available from the airport to hotels and from hotels to the Congress meetings.

To prepare for a World Congress that will have representatives from around the globe, who will be attending meetings that extend through five days, is a truly major task. The arrangements required in the 1980 Congress city—Winnipeg, Canada—are, in themselves, most demanding.

Winnipeg World Congress Committees involve hundreds of volunteers who serve on the numerous subcommittees with specific responsibilities such as accommodation, local transportation, entertainment, news media, security, medical/first aid, translators, publicity, hospitality, exhibition, and more. There are also special committees responsible for the International Film Festival, Photography contest, awards, and special events related to the Congress itself.

Winnipeg Convention Centre

Winnipeg Convention Centre, one of North America's finest convention facilities, is the site for the delegates assembling from around the globe. The Centre was designed from the ground up to provide universal accessibility for disabled persons in every feature of the building.

The modern, tri-level building incorporates sidewalk ramps outside the building, and throughout the interior for wheelchairs; telephones at accessible heights; and international access symbols indicating accessible facilities.

The Congress will make use of the Convention Centre's show piece, the Great Hall. The 78,000 square foot pillarless area will incorporate both exhibitions and a theatre in which plenary sessions of the Congress will be held.

The opening event at the World Congress will be an audio-visual presentation reviewing developments in rehabilitation, and the changes in attitudes towards disabled people during the last 25 years.

This will be followed by the Congress challenge: "Prevention—Integration, Priorities for the 80's." During the course of the Congress, a Congress product is to be developed—"Charter for the 80's." It is hoped that this charter will influence rehabilitation programs throughout the world, to focus on the prevention of growing causes of disabling factors and the integration of the disabled into the community.

Accomplishing this charter will give the Congress a true meaning and purpose for the next decade, as well as provide an impetus for "1981—International Year of Disabled Persons," as declared by the United Nations.

Plenary Session on Integration

The first plenary session will focus on "Integration" and will direct its concerns to the social reactions to difference; the fact that integration is the keystone to rehabilitation; and the point that standardization and individualization is the dilemma of the disabled.

This plenary session will be followed by sectional meetings. These meetings will deal with the components of integration and refer them to the educational system, community integration, vocational integration, integrated health systems, and social integration. Each of these sectional meetings lend themselves to specific subjects of discussion that will have the broadest possible interest to everyone in the field of rehabilitation.

Plenary Session on Prevention

The second plenary session on "Prevention" will deal with the subject from all possible areas. Presentations will include such subjects as:

- *pre-and-post natal concerns*
- *genetic counseling,*
- *immunization*
- *rehabilitation screening programs*
- *early detection and intervention*
- *early service and disability prevention*
- *the environmental hazards of pollution and noise*
- *accidents in the home*
- *traffic and occupational hazards*
- *social prevention through social security and economic guarantees*
- *impairments*
- *limitations*
- *dependents*

Special Workshops

There will be two major workshops during the Congress. The first will deal with "Disability and the Family" and the other will discuss "Participation of Disabled People in the Rehabilitation Process."

Disability and the Family

The special workshop dealing with disability and the family will examine subject areas such as:

- *Family as a provider of care—parenting*
- *the disabled child and parent groups—policy for family assistance*
- *social costs for disability—economic impact*
- *the disabled family—psychological impact of disability on the family*

Participation of Disabled People in the Rehabilitation Process

This special workshop will examine subject areas such as:

- *consumer groups—organization and function*
- *disabled people as service providers—the economic component*
- *self-determination in rehabilitation*
- *taking responsibility for one's own life.*

Special Interests

The Congress will also accommodate several special interest sections such as arthritis and rheumatism, cardiac rehabilitation, deafness and hearing disorders, emotional disorders, sex and disability, speech disorders—verbal and non-verbal, communications, leisure activities, technical aids, and others.

Each of these special interest sections will give attention to prevention components. Some of the special interest sessions will be related to component sessions being organized as sectional meetings.

Congress Exhibition

In conjunction with the Congress, there will be a major exhibition of aids, devices and equipment for the disabled. The exhibition will have a separate and special opening, on the evening before the Congress officially opens.

The exhibition will accommodate approximately 140 exhibits, and time will be allocated for the general public to have access to the exhibit area. The many exhibits will demonstrate, in a practical manner, what already is available, and what is on the horizon and beyond.

Interpretations

Simultaneous interpretation will be provided in English, French, Spanish and Sign Language in all Congress plenary sessions. In addition to braille programs, there will be a braille exhibit map.

Social Events

Finally, the five day program will not be all work. The planning committees are preparing a selection of special social events including a folklore presentation of the dances and costumes of many nations; opera; ballet; sporting events; theatre; gala dances; international receptions. Every night, there will be free entertainment accessible to all in the Convention Centre.

Pre-Congress Seminars

The week before the 1980 World Congress of Rehabilitation International, there will be special seminars in various Canadian cities. All these pre-Congress meetings have been organized in cooperation with the standing commissions of Rehabilitation International. Registration in all pre-Congress seminars will be limited in number and all pre-Congress seminars will be conducted in English only.

Post-Congress Tours

Two post-Congress tours are planned for Canadian and international visitors who may wish to see other parts of Canada. Therefore, an eastern Canada tour is planned which includes visits to Niagara Falls, Ottawa (the capitol of Canada), and Montreal and Quebec City, with their unique French flavor, and Toronto. The western tour will include Winnipeg, Banff, Lake Louise and Jasper, which are located in the unparalleled Canadian Rockies; Vancouver, and a ferry ride across the straits of Georgia to Vancouver Island.

Special Events

In conjunction with the 1980 World Congress there will also be a film festival and competition, as well as a Congress photography contest. The 1980 World Congress Film Festival will feature films that deal with the theme of the World Congress: "Prevention and Integration."

The award-winning films will be judged on both the professional quality of the film and the effectiveness of the presentation of the message or story. Photography entries are invited from all over the world and should illustrate activities related to the Congress theme.

Rehabilitation International, based in New York, is a non-governmental federation of organizations carrying out programs for disability, prevention and rehabilitation. Its membership includes 103 organizations in 62 countries. These organizations include associations, agencies and boards, governmental and voluntary groups, as well as six international organizations.

The Canadian Rehabilitation Council for the Disabled is a federation of provincial, regional and local organizations, agencies and institutions whose primary purpose collectively and individually is to meet the needs of the physically disabled in Canada.

1980 World Congress Symbol

The 1980 World Congress Symbol was designed by Theo Dimson, a renowned Canadian graphic designer.

The small interlocking circles represent integration of the disabled. The large interlocking circles represent global integration and cooperation. The outer circle symbolizes the globe.

Entry from the United States of America

Citizens or permanent residents of the United States can cross the USA-Canada border either way, usually without difficulty or delay. They do not require passports or visas. However, to assist customs/immigration officers of both countries, native-born United States citizens should carry some identifying paper such as a birth, baptismal, or voter's certificate which shows their citizenship.

Naturalized U.S. citizens should carry a naturalization certificate or some other evidence of citizenship in case they are asked for it. Temporary visitors in the United States who wish to visit Canada do not need visas.

For visitors arriving by camper or trailer, the Accommodation Committee, through the Manitoba provincial government, has arranged for the use of the Bird's Hill Trailer Park. This trailer park, operated by the province, can accommodate up to 2,000 units, and the facilities are designed to meet the needs of disabled campers. Those utilizing the trailer park will also be provided with free access to Manitoba's provincial parks.

Registration and Information

For further information on pre-Congress seminars, the exhibits, the film festival and contest, the photography contest, post-Congress tours, and *registration* for the 1980 World Congress of Rehabilitation International *(including hotel reservations)*, contact as soon as possible:

The Congress Secretariat
1980 World Congress
c/o Canadian Rehabilitation
Council for the Disabled
Post Office Box 1980
Winnipeg, Manitoba, Canada
R3C 3R3

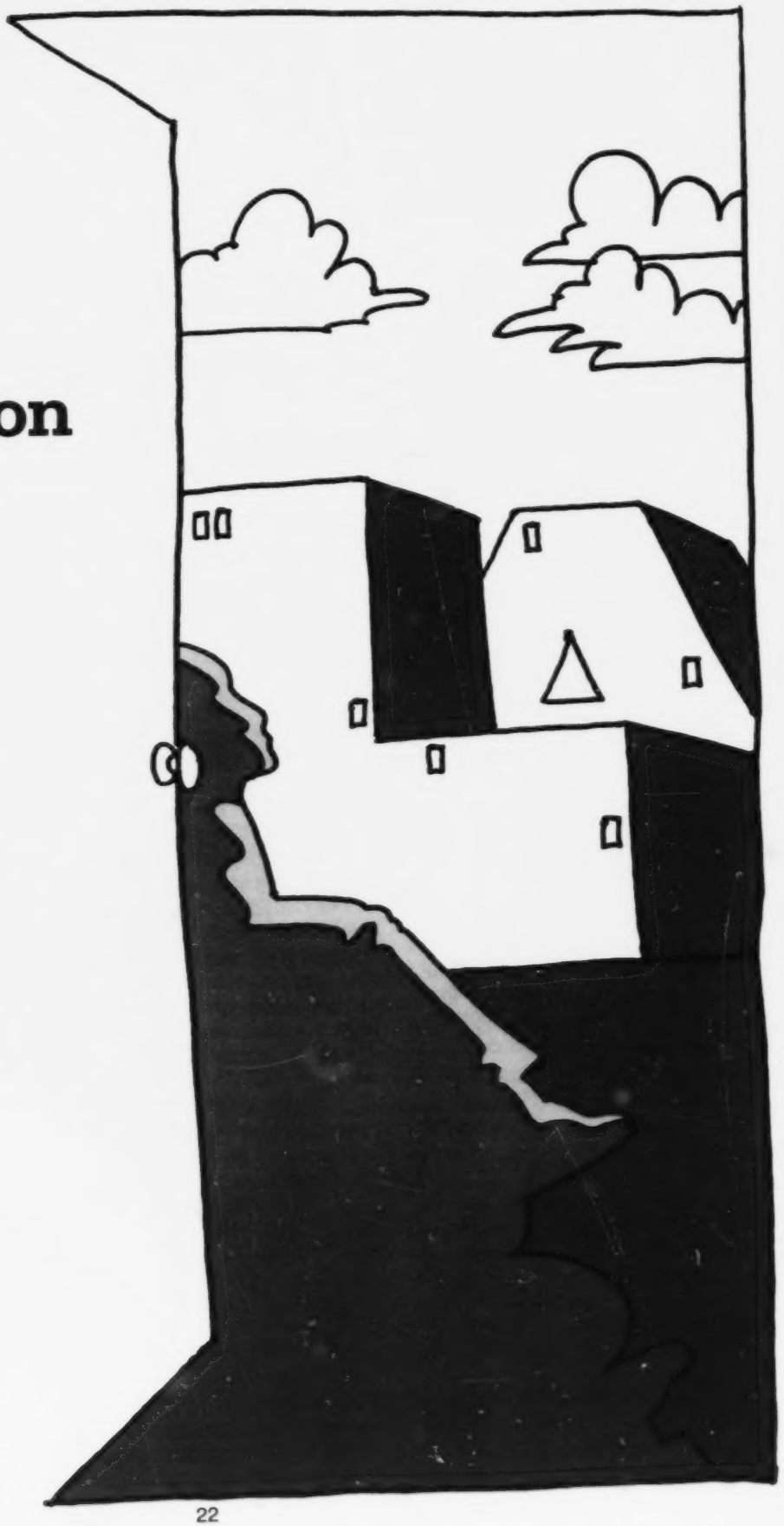
The registration fee for the World Congress is $225.00 prior to March 15, 1980. Following March 15, the fee will be $275.00.

—David A. White.

Mr. White is the director of National Program Services, Canadian Rehabilitation Council for the Disabled.

Mayor's Concern Brings Action

In Los Angeles, Tom Bradley's sensitivity to disabled constituents is coordinating resources to open new doors . . .



Tom Bradley took over Los Angeles' towering City Hall in the midseventies armed with a personal concern for the problems of physically and mentally disabled people. He acted on this concern by forming the Los Angeles Council and Office for the Handicapped, which offer disabled people real links with City Hall and a voice in the power structure. This action has afforded the mayor important links with a new political constituency; a constituency that knows no sexual, ethnic, age, cultural or socio-economic boundaries.

Will disabled people pay poitical dividends in response to the mayor's actions? The Los Angeles Mayor's Office for the Handicapped has enjoyed an outstanding record in attracting federal monies for programs for disabled people, while forming new ties with L.A.'s hard-to-reach ethnic communities by setting up special programs for ethnic handicapped people. Programs for the disabled also offer the mayor's office a new means of involving the business and private organization sectors with City Hall in solving the employment and other problems facing disabled adults.

The Council for the Handicapped is another means of reaping political dividends as it is set up to represent all sectors of the city, all disability groups, and the political interests that worked to elect Bradley. Of the 45 members of the council, 15 are selected by nominations submitted by organizations; 15 are appointed by the elected Los Angeles City Council; and 15 are appointed by the mayor.

The 45-member Council for the Handicapped's impact is further extended by assigning tasks to five subcommittees whose members are drawn from throughout the city's social and political structure. The staff of the Mayor's Office for the Handicapped represents many of the disability and minority groups within the city and provides yet another link to these hard-to-reach communities.

The office realized an immediate public impact by its success in attracting federal monies. The U.S. Department of Health, Education and Welfare's Rehabilitation Services Administration funded the initial organization and training of personnel for both the council and the Office for the Handicapped. Immediately after training, the council held public hearings on the needs for "independent living centers" for handicapped people, and the office provided seed money to help disabled consumer groups get these "centers" opened.

Armed by public and political support garnered by these public hearings and seed money, several "independent living centers" have been funded within Los Angeles. They provide close ties to the mayor's office while they reach into the disabled community through the provision of services.

With the exception of the space provided by the city to the Mayor's Office for the Handicapped on the 21st floor of City Hall, office personnel and programs are funded by the federal government. This success in attracting federal monies has allowed the office to become involved in a range of highly politically-visible activities, including job training, job placement in both the public and private sectors, housing, transportation, education, counseling and recreation.

The office reports a notable accomplishment in changing city codes, standards, rules and regulations to incorporate the interests and needs of disabled people. The effect of this is cummulative, and will impact on everything from the construction of municipally-funded buildings to the requirements of city jobs and licenses.

Department of Labor funds, through the Comprehensive Employment and Training Act (CETA), pay the salaries of office personnel, as well as the initial salaries (training slots) of disabled people placed by the office through the city government. Health, Education and Welfare's Rehabilitation Services Administration funds the "Projects With Industries" program through which the office trains and places disabled people in jobs with private industry.

Department of Housing and Urban Development (HUD) funds are being administered by the office in an innovative long-term, no-interest, loan program to enable qualified handicapped renters, apartment house owners, and home owners to modify residences for greater accessibility. Department of Transportation (DOT) funds are available for the purchase of buses; and pilot "mainstreaming" projects have been produced with Office of Education funds.

The impact of this federal money has been to give the Mayor's Office for the Handicapped considerable visibility without the expenditure of city money—a fact that any local taxpayer can appreciate. The mayor's consideration of disabled people as a viable constituency will do much to produce a constituency which can, in its turn, support those politicians who have demonstrated their concern for disabled people. As roughly 10 percent of the adult population of Los Angeles-Long Beach were found to be disabled (1970 Census), the mayor's interest could produce substantial rewards at the polls.

Similar statistics can be found for any large American city, and other mayors have recognized the potential political importance of their handicapped constituents. Mayor Bradley may have turned his concern for the problems of disabled adults into a mechanism for forming an important new political constituency. One sign that this may be happening is the recently-formed Los Angeles Young Democratic Disabled Movement.

—Robert H. Ruffner

Mr. Ruffner is director of Communications for the President's Committee. For further information contact: The Los Angeles Mayor's Office for the Handicapped, Room 2100 City Hall, 200 North Spring Street, Los Angeles, CA 90012.

A Word of Caution For the Eighties. . . The Wheel Has Been Invented!

Reinventing the wheel in the disability field has become standard practice. Part of the reason for this lies in the proliferaton of grants and programs triggered by recent legislation. Part of it must be attributed to the lack of shared information about disabled people and their programs.

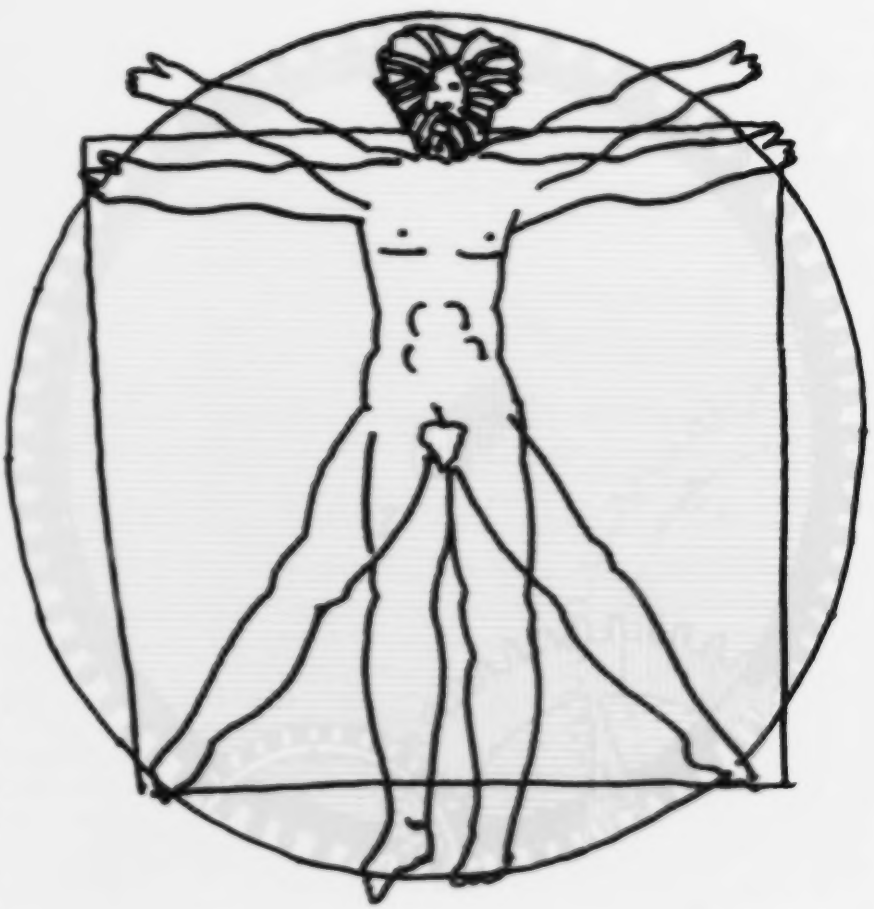
One example of the reinvented wheel is the hiring and promoting of disabled people by the federal government. A number of laws passed in the 1970's mandate government affirmative action for disabled people, including disabled veterans. For some agencies, this is new. Some agencies are maintaining that it is nearly impossible to find qualified disabled employees. Other agencies have been doing it for years.

The President's Committee is one of these agencies, and the 1970's have given the Committee considerable experience with the hiring, promoting, (losing to better offers), and the supervising of disabled employees. I'd like to share some of my own particular experiences.

First, it used to be difficult to locate disabled men and women in the job market. It's easier today, although it can still call for ingenuity.

I meet disabled people frequently because of my job. The very first person I was interested in hiring was on a college campus in Washington, DC. When I met her, I was giving a talk urging college students to become involved with disabled people. The time was the late 60's, and college students were concerned with a number of issues. The young woman was, at that time, a graduate student at the college and active in the concerns of the day—anti-war; civil rights; individual freedoms. She was also interested in the then fledging rights movement of disabled people, and was to become a leading advocate. She became an effective volunteer for the Committee when she realized that our goals were similar.

I wanted to hire her for a job in communications for which she had the skills



and a Master's Degree. By this time, she was out of school and unemployed. But her particular qualifications—commitment, knowledge of disabled people, and writing and verbal skills—did not show up readily on the government application form.

We decided on a 700-hour appointment, and then hired her following the expiration of this appointment on an "excepted appointment" (Schedule A) basis. These two tools for hiring disabled people are invaluable.

Subsequently, she successfully competed for new job openings and converted to permanent career status. Today, she is in a senior staff position at the Committee, where her wheelchair is a familiar sight.

While finding potential employees with disabilities has become easier in the last few years, imaginative outreach pays dividends. Notifying Office of Personnel Management's office of selective placement, and your agency's selective placement coordinator, are the first steps.

Other useful contacts are organizations of disabled people, both national and local. Don't overlook the growing number of disabled employee groups within agencies. National organizations include the National Association of the Deaf, the American Coalition of Citizens with Disabilities, the American Council of the Blind.

Encourage your agency to exhibit at conventions of disabled people and organizations serving disabled people. The President's Committee has a yearly "job fair" at its Annual Meeting in Washington, DC, another opportunity to reach out to disabled people.

Contact the placement offices of colleges which specialize in education for disabled people, such as Gallaudet College in Washington, DC, the University of Illinois, Long Island University, St. Andrews College in North Carolina, and Hofstra University in Long Island, NY. Don't forget local four-year and community college placement offices either; it is likely that most schools will have some disabled students—and increasingly, disabled student advisors, clubs, and offices.

Resources in the Washington, DC, area alone include the District of Columbia Protection and Advocacy Office; Rehab Group, Inc., of Falls Church, Virginia; the Northern Virginia Center for Retarded People, Fairfax, Virginia; the Information Center for the Handicapped; Goodwill Industries; the several halfway houses; the District's Sharpe Health School.

Alert local rehabilitation and public employment offices of your interest in hiring disabled people. Advertise your agency's interest in disabled people in publications which have disabled audiences.

The new awareness among disabled people that they have rights to a job suited to their education and interests is having an impact on the availability of potential employees with disabilities. In the past, some disabled people didn't apply for jobs because of fear of rejection. The affirmative action sections of the 1973 Rehabilitation Act, increased public awareness of disabled people, and the active consumer movement have all contributed to encouraging disabled people to prepare themselves for the job market and to seek jobs.

Another disabled person who I wanted to bring on the Committee staff was a Vietnam veteran with a 100 percent disability because of blindness. He has some side, but no frontal, vision. He also has a doctorate degree and is forceful and ambitious.

Again, I met him in the early 70's through my work with the Committee, at the time when I was setting up a task force on disabled Vietnam veterans. A job opened, he was well qualified for it, and he was hired. He proved a real asset to the Committee, and has since moved onward to a responsible job in another agency. Being hired by the Committee helped to give him a boost in furthering a successful career.

Another coworker is a young deaf woman who was working on the Committee staff as a clerk/typist. She was interested in writing, however, and wanted a better opportunity. Profoundly deaf, she was a graduate of Gallaudet College and was well on her way to a master's degree (which she has since obtained.) She showed talent and initiative.

In this instance, we did some trading and shuffling of people. She applied for, and won, again on an "excepted appointment" basis, a job as a writer and has since moved up to a more demanding job.

But there are setbacks. A few years ago, I hired a woman in her 40's who had spent many years in mental institutions and who was on a "work-release" program from St. Elizabeths Hospital. She was a fine worker and seemed to enjoy her job as a clerk/typist. She readily accepted and produced assignments.

She kept to herself. She had some habits, such as talking to herself and carrying on imaginary phone conversations, which could have been disturbing to other staff members. Upset was avoided by talking with the staff about the difficult life that this woman had led. People responded and were pleasant.

In a way, the Committee became her haven from a world of turmoil. We had frequent conversations and got along very well. I was anxious to extend her beyond her initial 700-hour appointment, so we hired her on a one-year temporary hire when her 700-hour appointment expired. This gave us the opportunity to evaluate her before hiring her on a permanent basis.

When she stopped seeing her doctor and taking her medication, she began to hallucinate. Her hallucinations were interfering with her work, and one day I suggested that she see a doctor.

I never saw her again. She made some threats in telephone calls and

refused to return to work or seek help. She left the city. The Committee was notified of her death some months later.

This experience didn't deter our hiring another person from the "work-release" program at St. Elizabeths. This person lived in a psychiatric halfway house, took medication, and saw the doctor regularly. Again, we had a fine and talented worker who has since left the Committee for a better job with another agency.

The men and women I am discussing are only some of the disabled people the Committee has hired and promoted during the 1970's. The Committee has attracted talented disabled people from throughout the country; people willing to change jobs and leave their hometowns. It has been a success for both the employees and for the Committee.

My own office produces award-winning national programs of education and information about disabled people. Disabled people, both on the staff and on contract, help produce these programs. The disabled people on the Committee are in constant demand as consultants, advisors and resource people by other government agencies and private organizations.

I mentioned earlier that I was fortunate in being with an agency with experience and familiarity with physically and mentally disabled people. Some of the other questions which arise concerning the hiring of disabled people are about accommodating and supervising. What are the special requirements, if any, of disabled people?

Our offices are located in a reasonably accessible building in downtown Washington, DC. There is a ramp in the basement garage which enables people in wheelchairs to enter via the garage. The Committee provides parking spaces for employees with mobility limitations, regardless of their salary or grade.

The restrooms on our floor were remodeled when we took the space. We have equipped our office with TTY's (telephone/typewriters for people who are deaf); we have a staff member skilled in sign language interpretation who translates for employees (and others) with hearing impairments at staff meetings and on other occasions as needed.

The Committee staff is generally sensitive to the needs of disabled people and is helpful if called upon to handle unusual situations. I recall one meeting a few years ago when a young man had an epileptic seizure in my office. A coworker brought a glass of water and, when he came out of his seizure, he sipped the water as we continued our conversation. In fire drills or other evacuations, a safety drill has been organized to assist people in wheelchairs out of the building. Readers for blind employees are provided as needed.

Reasonable accommodations have been made — changes and alterations that don't run up excessive bills. Many of our solutions are common sense. A problem is identified, a solution is sought, and usually found without any great strain.

An example might be the elevator in the building which services the basement garage. The call button for this elevator is quite high up on the side of the elevator door. One employee, who used a wheelchair, could not reach up to the call button and would have to wait in the hall until someone came by to push the button for her. One of the staff saw this one day and the next day installed a stick on a chain which does the trick by eliminating any need for a passerby to have to push the call button. Simple, inexpensive, and ingenious.

I spend time listening to, and counseling, all my employees, including disabled workers. Some disabled people seem to invest more of their lives into their jobs. At any rate, my one-to-one counseling pays off as ours is a talented, creative group of people with a flair for the national communications program which we are running. I think that some of the counseling is due to creative people's craving for understanding and recognition.

As far as time and attendance goes, there is no significant difference. One of our disabled staff members had an unusual disability-related accident which landed her in the hospital for seven months, but accidents happen to anyone. Other disabled employees from time to time check into a hospital for a week or two but, for the most part, disabled employees are at their jobs as much as anyone else in the office.

Disabled employees are treated as all other employees. They don't seek sympathy or make excuses to avoid work. They are expected to perform their duties fully.

The Committee's disabled employees travel on their own; represent the Committe at meetings throughout the U.S. and abroad; staff exhibits at major conventions; interview people for magazine articles; speak at meetings and seminars; and fully share in the Committee's responsibilities. Summarizing the experiences which I have had with finding, hiring and promoting disabled employees during the past decade, I can only conclude that the disabled employees I know are making significant contributions to the President's Committee and to the federal government.

The 80's will see more talented disabled people in the job market. The programs are there to utilize these talents. We don't need to reinvent the wheel—just make good use of it.

—Robert H. Ruffner

Mr. Ruffner is the President's Committee's director of communications.

Policy Changes To Open Jobs For the Handicapped

The Director of the U.S. Office of Personnel Management (OPM), Alan K. Campbell, has announced an important change in policy which will provide more federal white collar job opportunities for the handicapped.

The old lengthy and overly restrictive physical requirements sections in the OPM Qualifications Handbook for General Schedule Positions have been replaced by a single medical qualification statement for all positions with sedentary, light, or moderate duties. In effect, the new policy requires only that applicants be physically and mentally able to efficiently perform the functions of position without being a hazard to themselves or others.

Qualification standards for occupations that typically involve arduous or hazardous duties remain in effect, but also have been modified to reflect additional pre-placement considerations.

"The changes reaffirm the federal government's commitment to hiring the handicapped by requiring job applicants and employees to possess only the minimum medical qualifications necessary for safe and efficient performance of the duties of a particular position," said Campbell.

While certain positions may have essential duties which require usable vision, color vision, or speech, in most cases, a specific physical condition or impairment will not automatically disqualify an applicant for appointment. Reasonable accommodation may also be considered in determining an applicant's ability to perform the duties of a job.

Specifically, the new policy will enhance employment opportunities for the handicapped by:

—Delegating more authority to federal employing agencies to determine the medical eligibility of an individual applicant for a position, based on the actual tasks of that specific position, and on the demonstrated abilities of the particular applicant;

—Encouraging the use of reasonable accommodation, job restructuring and worksite modification; and

—Emphasizing the need to interpret and appropriately modify occupational medical standards to reflect the minimum requirements of the specific position to be filled.

The changes resulted from a recent OPM review of existing medical requirements in General Schedule qualification standards. This review indicated that many jobs could be performed by handicapped persons if the physical requirements were revised.

(Taken from an OPM press release.)

The Chairman's Column

NEW EDUCATION PROGRAM . . . The American Association of Colleges for Teacher Education (AACTE) has announced the start of a project titled "Section 504 and Teacher Education." The purpose of the project is to collect and identify information on disabled people in the education profession. The information collected will be used to identify and explore barriers obstructing the entry and full participation of disabled persons to training and employment as teachers, school administrators, and education faculty.

Funding for the one-year project comes from the Office of Civil Rights of the Department of Health, Education and Welfare through the American Council on Education's Project on Higher Education and the Handicapped (HEATH).

In order to ensure the success of the project, AACTE needs the consultation of disabled individuals in the education field. If you are a disabled teacher, administrator, or student, faculty member in a school, college, or department of education, please identify yourself to the project at the address below.

The project is also seeking to identify disabled people working in areas of education other than teaching and administration such as federal, State and local education agency employees or officials and teachers' aides.

Finally, the project seeks to identify disabled people who have been prevented or restricted from training or employment in education due to their disability.

The project address is: Section 504 and Teacher Education Project, AACTE, Suite 610, One Dupont Circle, N.W., Washington, DC 20036. (202) 293-2450. Names of individuals participating in the project will not be used without permission.

BUYER'S GUIDE . . . The 1980-81 *Accent Buyer's Guide* is now available. This new edition answers hundreds of questions for disabled people. It lists many common activities of daily living and provides the name and addresses of companies that have products and services available. Over 400 items are indexed for easy cross-reference. New products have been added, and old ones deleted, assuring the user of a current shopper's list from which to select. To order, write: Accent Publishing Company, Gillum Road and High Drive, P.O. Box 700, Bloomington, IL 61701. Price: $10.00.

FUNDING DIRECTORY . . . Research Grant Guides has just announced the publication of the updated 1980-81 edition of the *Handicapped Funding Directory*, a resource of information for planners and fund seekers for the handicapped.

Edited by Burton J. Eckstein, the *Directory* lists over 400 foundations, associations, and government agencies for handicapped programs and services. In addition, it includes articles on how to obtain a grant, what a reviewer looks for in an application, and gives names and addresses of State agency directors, and a bibliography of grant funding publications. The book is in paperback. To order, write: Research Grant Guides, P.O. Box 357, Oceanside, NY 11572. Price: $16.50.

ATTITUDES ... Is it possible to change attitudes and behavior toward handicapped persons through media? Two years of research at the University of Southern Maine suggest that it can be done, provided the media presentations are carefully designed.

Two 16mm movies, based on the design principles, are now available: "First Encounters," which deals with the discomfort experienced when meeting a physically disabled person for the first time; and "The Invisible Barrier," which examines cultural stereotypes and barriers to accepting physically disabled people as fully functioning members of the working world. For further information, contact: Stephen Beam, Disability Information Center, University of Southern Maine, 246 Deering Avenue, Portland, ME 04102. (207) 780-4430.

SIGN-A-TEE ... is the name of a company that markets tee shirts, tote bags, greeting cards and other merchandise with designs based on sign language and deaf culture. Sign-A-Tee carries original designs by deaf artists, and also has a fund raising plan for organizations interested in raising money. For a catalog or information about the fund raising plan, write: Joe Dannis, President, Sign-A-Tee, 8043 Sandy Spring Road, Laurel, MD 20810.

DISABLED WOMEN ... The Disability Rights Education Defense Fund, a division of the Center for Independent Living in Berkeley, California, has received a grant from the Women's Educational Equity Act in Washington, DC, to conduct a study on the educational needs of disabled women.

They are seeking disabled women who have experienced any type of educational setting, and who would like to be interviewed concerning their experiences and opinions. This information will be used to support guidelines for future funding priorities for disabled women. If you are interested in sharing information with them, please drop a note with your name, address, phone number, age, disability, type of educational settings experienced, and the time you prefer to receive phone calls, to: Shelley Bergum, CIL/DREDF, 2539 Telegraph Avenue, Berkeley, CA 94704. (415) 548-4274

NUTRITION ... Providing good nutrition for immobilized disabled persons is a challenge to all who are involved in their care. *Nutritional Care of the Physically Disabled* is a new book containing information for health professionals who provide nutritional care and education to disabled people.

Written by Madelyn Hargrave, the book describes problems associated with disease and inactivity in eating, digestion, elimination, skin; nitrogen, calcium and energy metabolisms; and fluid and electrolyte balance. Special sections focus on how to plan a nutritional care program, dietary modifications for diabetes and hypertension, and nutritional care of the elderly disabled. To order, write: Research and Education Department, Publications Office, #299, Chicago Avenue at 27th Street, Minneapolis, MN 55407. (612) 874-4175. Price: $6.50.

Harold Russell

THE PRESIDENT'S COMMITTEE
ON EMPLOYMENT OF
THE HANDICAPPED
WASHINGTON, D.C.
20210

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THE PRESIDENT'S COMMITTEE
ON EMPLOYMENT OF
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VOL. 3 NO. 5, 1980

DISABLED

3/5

A little bit of everything . . .
medical student with a disability . . .
new book review . . . tax credits save employers'
dollars . . . a potpourri of stories!

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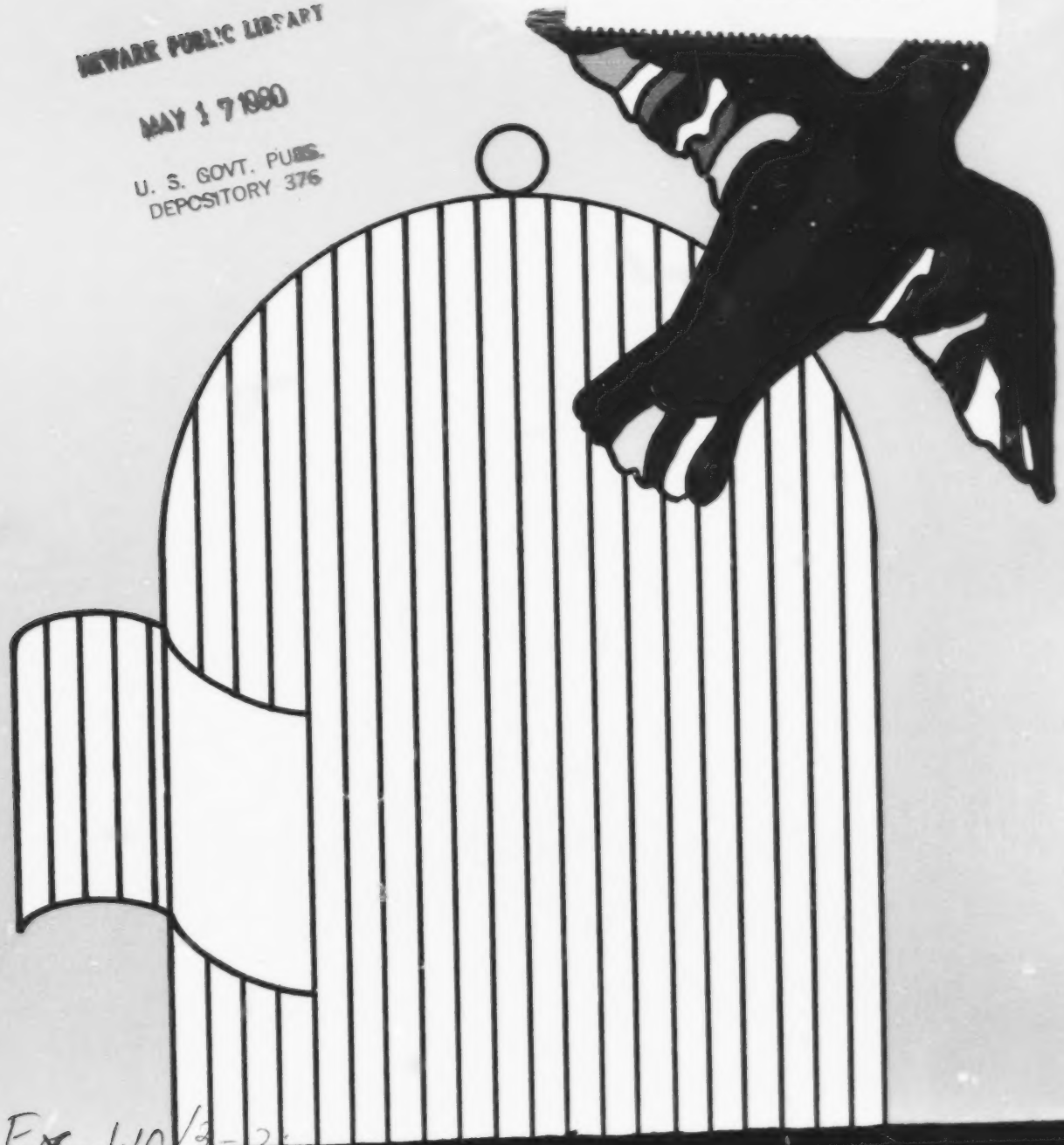

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DISABLED

VOL. 3 NO. 5, 1980

In this issue we focus on a variety of topics, from a discussion of the disabled consumers movement to an outline of how employers can gain tax credits. Hopefully, something for everyone.

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FREE THE PEOPLE
In this story a disabled activist outlines some of the philosophy behind the consumers movement. She points out some of the problems disabled consumers face — and some potential solutions.

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REHABILITATING AMERICA: A PLAN FOR THE '80's

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A DOCTOR WITH A DISABILITY: A UNIQUE VANTAGE POINT
A visible disability facilitates the doctor-patient relationship. Steve Madigan, a medical student who uses a wheelchair, discusses this and other issues surrounding disabled people and the medical profession.

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THE DAY I CUT THE GRASS AT RFK STADIUM

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LIFE WITH TOURETTE SYNDROME
Life with a syndrome that few people understand can be an excruciating experience. This story focuses on Tourette Syndrome — a problem whose symptoms have only recently been identified and treated with some degree of success.

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CHAIRMAN'S COLUMN

Chief Executive Officer
Deputy Director, Executive Office
Vice President
Editor-in-Chief
Managing Editor
Art Director
Circulation Director
Marketing Director
Production Director
Controller
Director, Administrative Services
Director, Information Services
Director, Membership Services
Director, Publications
Director, Public Affairs
Director, Special Projects
Director, Technical Assistance
Director, Training
Director, Washington Office

DISABLED USA supports Executive Order 11914 which prohibits discrimination on the basis of handicap in federally assisted programs and activities, and Executive Order 11914 which requires affirmative action to employ and advance in employment qualified handicapped individuals in federal employment. DISABLED USA encourages all programs and activities receiving federal assistance to comply with the provisions of these Executive Orders.

The Department of the Treasury, Office of Revenue Sharing, has determined that the publication of this periodical is necessary in the transaction of the public business required by law of this Agency. Use of funds for printing this periodical has been approved by the Director of the Office of Management and Budget through August 15, 1981.

DISABLED USA encourages the submission of articles for publication by all readers, especially disabled people. Articles should be eight to ten typewritten double-spaced pages, written in any format style. We also welcome letters from readers for the RSVP column. (All articles appearing in DISABLED USA may be reprinted with or without credit.)

Free the People

I was given as an activist in disability rights activities in and around Louisville, Kentucky. What is even more important about Cass than her activities, though, is her approach to disability, and to the disability rights movement. In the following interview, Cass talks about what the movement needs to help it gain the momentum it seems to lack locally, and, to a lesser extent, nationally.

Her thoughts won't please everybody.

As the interview begins, we are beginning to discuss some philosophy.

CASS: There are two aspects involved in the issue of civil rights for disabled people. One aspect is disabled people themselves. The other aspect concerns the expectations of an able-bodied society about what disabled people are supposed to be.

ME: *What do you think has caused disabled people to lag behind in starting their own movement?*

CASS: Simply, because they've been oppressed. I know that sounds simplistic, but how can you fight for your own rights when you cannot get to the arena? How can you demand an equal education if you can't get to the seats of government? How can you overcome your feelings of inadequacy if no one gives you any positive reinforcement?

It's very important, when you're trying to make any changes, that you have reinforcement. If you're isolated, if you're at home and your family's taking care of you, then you may have some good thoughts about equality, but you don't have any strong group supporting you.

Disabled people do not have any sense of brotherhood among themselves. They do not have traditions to fall back on; no history of suffragettes of the last century, or of the civil rights leaders that other minorities use to shore up their lagging spirits. They don't, really, even

"Disabled people don't yet have any legitimate leaders who are like Martin Luther King, saying, 'I've been to the mountain, and I *know*.'"

organized with the people.

ME: *Why has the emphasis been so much on these "intricate problems," rather than on the basic first step of organizing the people? You imply that we have a need for services, yet a more basic problem with accepting those services as our right.*

CASS: True. This nation says that everyone is equal, but individuals are told: "Well, yes; but then you've got to understand that it's gonna be a little harder for you than for other people. You've got to be patient—and of course you deserve the equality everyone deserves, but it's gonna be harder for you because you are, you know, a little bit different, really. . . . Let's face it: you just aren't able bodied, after all."

ME: *You're saying that our nation says one thing, in general terms, to disabled people, and on the other hand, individually to disabled people, it says something entirely different, and disabled people are believing that version.*

CASS: Exactly. If disabled people didn't believe that themselves, they'd say, "You're full of ....., and *we demand* our rights."

ME: *Why is it that you have been radicalized and some others have not? Why don't they know these things, and what will it take to help them become aware of them?*

CASS: It's gonna take a lot of propagandizing. It's going to take people sitting there and saying to disabled people, "Damn, you *are* as equal as anybody else, and you should demand your rights." It's simply going to take a lot of convincing. I call it "freeing the people."

It's not something that just happened to me. I started the process first by thinking about it all—about the injustice, the discrimination, the powerlessness—and at some point, I began to look at it objectively. I kind of enjoy having to prove a point about disability rights now; it isn't something that I felt so easy about at first.

ME: *Service-providing agencies are supposed to be counseling disabled people about their rights. Are they actually counseling disabled people the way you think it should be done? It doesn't seem that, on the whole, many disabled people feel as you do, and yet they're supposed to be getting counseled on their rights.*

CASS: Well, they're *not* being counseled about their rights. In the case of the disabled person, the rehab counselor who is doing the counseling has already "made it" in an able-bodied world. He's successful—whether that rehab counselor is disabled or not—and he's going to be caught up in believing in the same old system that keeps saying to all disabled people, "Well, you're as equal as everybody else, but this is going to take some time, after all." In other words, wait, and don't push.

Disabled people don't yet have any legitimate leaders who are like Martin Luther King, saying, "I've been to the mountain, and I *know*!"

ME: *Why do you think that is?*

CASS: Because disabled people find it very hard to believe that other disabled people are going to be better than what they think the lot of disabled people is supposed to be.

Disabled people need more spirit. They need more inspiration. They need some passion. Very simply, they've got to develop a pride in themselves as a disabled people—a group pride.

ME: *How could this come about?*

CASS: The people who are leaders right now in the movement are going to have to start talking about "gimp pride." They're going to have to start stating to themselves *why* they're equal, explaining, knocking down all of the old "regular" concepts that just aren't working, and quit talking all the time about us needing "special" services. They're going to have to start talking *to* the people before they can speak *for* the people.

ME: *There are some people who are supposed to be leaders—they have attained high positions in the government, and they are disabled. From what you have said, you don't seem to feel that they are offering disabled people a sense of pride or unity.*

CASS: They're not really working with disabled people—they're working with the system. I really hate to put forth the view that disabled people are their own worst enemy, but. . . . It's certainly not their fault that they're their own enemy, but I think it is the fault of the leaders.

They may want disabled people to write a bunch of letters, but they're not saying, "Don't just write a bunch of letters; get involved!" And they're not going back to the people and saying, "Not only do I want you to write letters; I want to sit down with you and talk to you and find out what else you can do."

Disabled people probably write more letters than any other group in the world, but they're not getting anywhere by just writing a bunch of letters. You go to the politicians and say, "I've got 50,000 people here who need services," and they say, "I don't see them." And they get a bunch of letters, and they think "that's nice," but they still don't *see* them.

And of everybody who has started getting involved with the movement, I think there have been only one or two people who have really been important to the people—only one or two who could "talk a good rap."

ME: *In other words, showing disabled people the common thread, or the ideology, that's going to make disabled*

"Our society believes that everybody's equal . . . on the surface; but they don't like something that's different. They don't like that at all."

people realize once and for all where they're coming from and where they ought to be going. But what is it that we've got to tell disabled people? You say that we've told them they're equal, and that that doesn't work.

CASS: No; well, we've got to prove it, as I said earlier. You can't say you're equal, and then try to go through a building and find out you can't.

ME: *So which comes first?*

CASS: They both have to come at the same time. What's happening now is that the government is beginning to relate to disabled people, it's beginning to provide them with laws and opportunities, but nobody's working with the disabled people.

What we're finding right now is that colleges are opening up, employment is opening up—and nobody's going, nobody's jumping on those opportunities because they don't know about them, or they aren't in a position where they can accept them. And if they do try, quite often they aren't socialized enough to handle it—I was that way—and so they become failures, of a sort (or they think they are), and they run back home.

ME: *So, in a very basic sense, you're talking about consciousness-raising.*

CASS: It is, but I'd like to take it further and call it "organizing". When you really look at it, the civil rights movement in the 60's got on its feet because there were a *lot* of people who were saying, "We need to get some things changed."

In the civil rights movement, there was a great deal of support from white people who were authority figures. Now the white people didn't say, "You nice little black person, I'm gonna help you." No. They'd say, "Let's fight for this thing together, because we are equal. We are truly brothers." And they believed it.

Now, able-bodied people are not doing that for disabled people. I have found very few able-bodied people in this movement who really believe that we are as equal as they. Oh, they espouse it, but you can see that they constantly perceive differences. The bottom line is that you've gotta believe, way down in your soul, that we're all equal. If you don't, then just leave us alone.

ME: *Aren't you talking about credibility? Are you saying that able-bodied society, despite all its laws and all its interest, deep in its heart does not really believe that disabled people are equal?*

CASS: Exactly.

ME: *What is it going to take, then?*

CASS: It's going to take instilling a pride in disabled people, at the grass roots level, that will flow up from the bottom and culminate at the top. It will then be a force to be reckoned with.

At that time, disabled people will be able to force society, as it were, to take at face value what they mean. Because if disabled people do have that pride in themselves, you see, they'll start proving that equality.

If people would quit saying they're equal, and meaning by it that they're the same, and start saying instead that "we have a right to our own way of life, and my way of life is just different from yours. It isn't more or less, it's just different," we'd be on the right track.

Our society believes everybody's equal, and they like *that* concept on the surface; but they don't like something that's different. They don't like that at all.

ME: *So you're not talking so much about being equal, meaning "the same," but about individual freedom to choose options.*

CASS: Exactly. And to know, whatever way you live, if that's what you want and if that's a successful lifestyle for you, then it's just as acceptable a way as any other way.

All the problems disabled people have with being considered "less than normal" are problems that stem from people having to have a standard. And when you fall below that, if you're different from that, you *aren't* equal. Because you *aren't* the same.

ME: *And you're implying here that the standard is really an arbitrary one set up by an able-bodied society?*

CASS: It is; and I don't know how much it's set up by able-bodied people and how much it's set up just by the circumstances of today. Like having to work eight hours a day, five days a week, and having to have a home and two cars, and having to pull one's own weight in order to be decent, and having to achieve the things we're all supposed to achieve for a successful life.

Disabled people, most of the time, will always be dependent on someone; but that doesn't mean they're not independent. It's just that our connotations are so, well, erroneous, that it becomes extremely difficult for a person to consider his lifestyle successful when it is different from that which is espoused as successful.

If everyone had accepted everyone exactly for what they are, then there wouldn't have to be any civil rights movements in the first place. We can't change the concepts of the whole country. But all that has to be done, instead of having to change concepts of what is "right," is simply to accept disabled people's modes for what they are.

Today, all this may sound quite weird. Twenty or thirty years from now, though, someone's gonna say (just like somebody said to me recently after I'd been discussing disability rights with a bunch of people), "Well, of course. It makes perfect sense. Why would anyone think any other way about disability?"

ME: *Disabled people themselves, you're saying, are going to have to be*

"Like Janis Joplin said in her song, 'Freedom's just another word for nothing left to lose.'"

the ones to enforce the changes.

CASS: Well, they are; they definitely are. Black people ran their own movement; women are directing the women's movement; and disabled people have got to come out of the closets—the successful ones—and help those who aren't as aware as they should be, to fight for their own rights.

ME: *You often seem critical of those disabled people who you term "successful," implying that they have the power to influence other disabled people; to change things. You say that "they work in the system, and not with the people." At other times I've heard you refer to them as "Uncle Tiny Tims." Will you expand on this concept?*

CASS: Well, there are similar instances in other movements; of the black attorney who's worked his way out of the ghetto and won't be caught going back. It's not "cool" to be involved in the disability rights movement.

So, of course, yes, you believe architectural barriers should be removed because they bother *you*, but you're not going to use *your* energy on barriers, because you might have to work with a bunch of people you don't like, and who you don't really accept—that is, other disabled people.

And, after all, you've made it in spite of your handicap; others can hire an attendant who will help them through doors and up steps. They've got to overcome their handicaps too, just as you did.

Disabled people don't like each other very much. I know we're not supposed to talk about this divisiveness openly, but it's sadly true. It's not a case of one disability group arguing with the others.

I'm talking about individual contact. Disabled people would never starve themselves, go to prison, or be forcefed for the rights of another disabled person. Not yet. They don't really believe they're equal, even with each other.

It's the old "I worked my way up from the bottom. You can too. And if you're not as good as I am, then, of course you don't deserve it." That's a bunch of ..... Everybody deserves rights.

So, whatever it takes, at the bottom—I think in other movements it took a lot of blacks, and a lot of women who were either dedicated to change or just so desperate, that they just decided they were going to find out what it took to get themselves out of the mess—now that's what has to happen right now for disabled people.

Like Janis Joplin said in her song, "Freedom's just another word for nothing left to lose."

Disabled people think they have too much to lose to want to try the desperate route. And the reason that disabled people are not organizing—that is, another reason—is that they are not together. Physically isolated.

When it comes to the movement of disabled people, as a group across the country, it's just like the 1920's or before in the civil rights movement. And because of that, there needs to be a great deal of focus on working with disabled people.

I work with a lot of committees and such, and recently it occurred to me that my greatest mistake, all this time, has been that I try to get people involved who aren't at my level of consciousness yet about disability rights. They're just not interested in it. They don't have time for it. I find it most curious, and very unsettling.

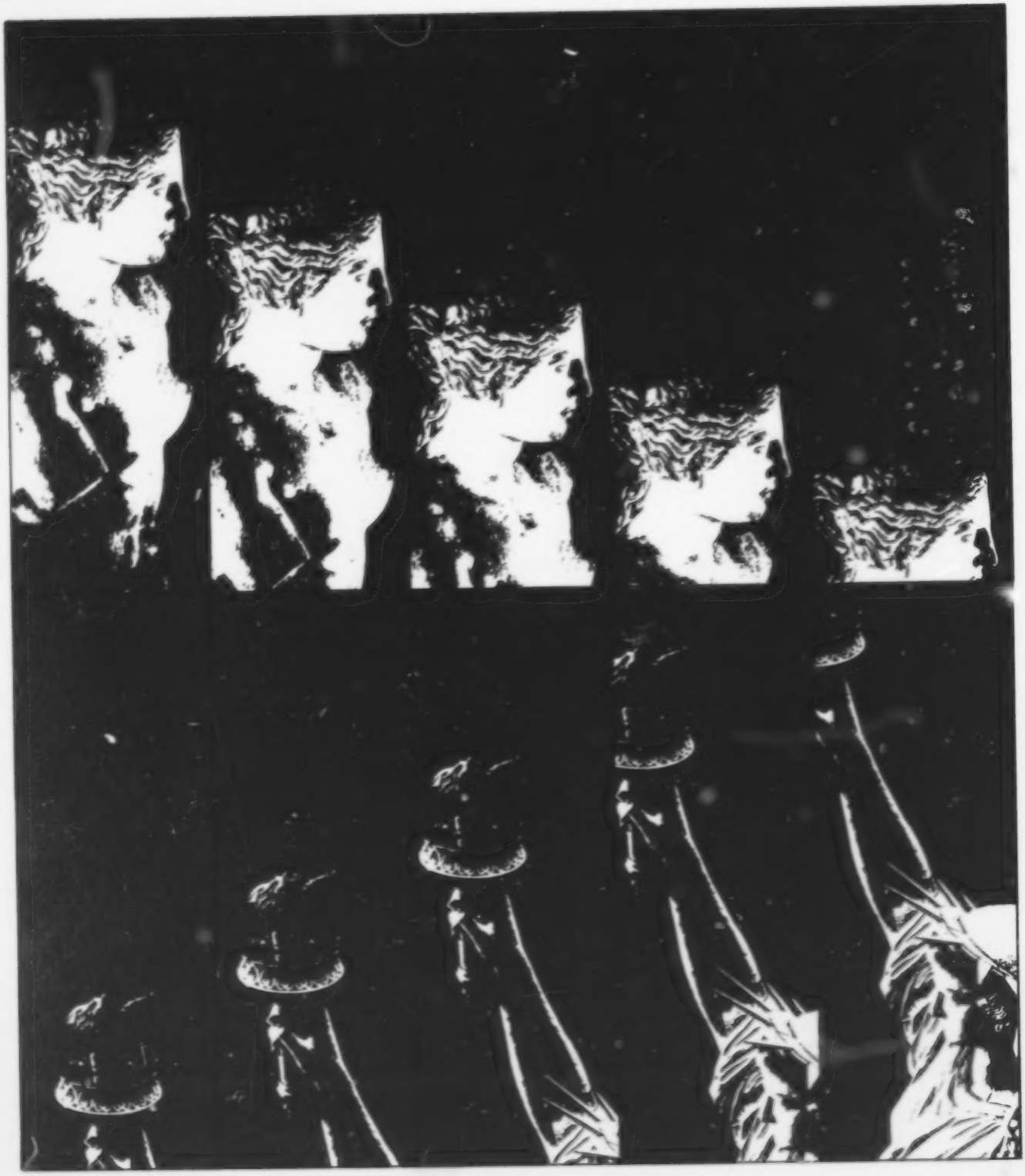
But lately it's made me realize that what I have to do is start getting involved with these people, who, in reality, are actually more oppressed than I ever was. I need to go to them and say, "Look. You're going through the same problems all the time—with your personal transportation, your housing woes, your desire to go to a good restaurant that's accessible. Don't you think it's time for a change? Don't you think you have any rights?"

The people need to be talked to; one on one, if it takes that. They need to really know and want their rights, and believe in them. That's only going to start happening when we start organizing.

When we start freeing our people.

—Mary Breit

Ms. Breit is a free-lance writer.



Rehabilitating America: A Plan for the 80's

Rehabilitating America, Frank Bowe's latest book, is important. He defines the problems facing the integration of disabled and elderly people in our society. He tackles difficult issues: Costs, segregation, poverty, prejudice. And, he is not timorous in discussing the exploitation and rip-offs that are taking place in the name of "helping the handicapped."

The reason the book is a "plan for the 80's" is Bowe's bold proposal to commit $22 billion a year for approximately 10 years to effectuate a five-point program which he considers necessary for the liberation of disabled and elderly people.

Rehabilitating America is subtitled "Toward Independence for Disabled and Elderly People," and Bowe is, through the subtitle and the book itself, making another proposal: To link the causes of disabled people with those of elderly people, forming a cooperative effort to better both.

A few years ago, when disabled Vietnam veterans were providing much of the impetus to the fledgling disabled consumer movement, linking with the elderly groups (which were then riding the crest of public recognition of their needs) was anathema.

The image disabled people wanted was that of "youth and vigor," and the elderly wanted to be considered "strong and healthy." The reluctance was on both sides. Perhaps the new realities of the fragility of the independence movements of all minority groups, and the growing threat to social financing, has brought about a recognition of the need for cooperation between disabled and elderly people.

Bowe's book is certainly a strong step in the right direction. By including the interests of both groups, he widens the number of recipients, the impact, and the political potential of his ambitious five-point plan.

It is a costly scheme to present at this time in America. Naturally, there is Proposition 13 fever to contend with. There is also ominous, ever-growing, inflation. Now, there is also war talk, draft talk, talk of more monies for defense and less for social causes. Without money, the disabled and the elderly consumer movements, the legislation, the new programs, will falter and possibly collapse.

Bowe defends his use of money wisely and well. An example is in his discussion of the concept of "separate" transportation schemes:

"Designing for access involves one-time costs for renovation and design; thereafter, no appreciable additional expenses are involved. Special services, by contrast, require extra vehicles, more manpower, additional fuel, and other operating and maintenance costs, and these costs are continuous, year-after-year expenses."

Other costs, such as the alarming 500 percent rise in the costs of Social Security Disability Insurance (SSDI) in the past 10 years can also be contained, Bowe believes. But, again, it requires the will to make the necessary changes.

"One of the most tragic aspects of the program (SSDI) is that it actually discourages disabled and elderly individuals from seeking and obtaining work. The disincentives, together with our country's failure to invest adequately in rehabilitation, prevent all but 1.5 percent of SSDI beneficiaries from returning to work."

Bowe uses case studies to dramatize the devastating impact of the income limitations of both SSDI and Supplemental Security Income (SSI) on people's lives.

Bowe's "five-point plan" is: 1) Expand research, development, and technology-transfer efforts. 2) Remove architectural, transportation, and communication barriers. 3) Train disabled and elderly people in overcoming their disabilities and tapping their abilities. 4) Reform dependence-oriented programming. 5) Make our communities "open" to, and useable by, disabled and elderly people.

Each of the five points is examined in some detail, and several are backed by statistical examination and opinion polls. He substantiates the cost benefit of rehabilitation programs, and discusses some of the exciting potential of new programs in education and employment.

In the chapter, "The Open Community," Bowe touches on attitudes and the need for information. He also acknowledges the responsibility which elderly and disabled people themselves must shoulder to effectively rehabilitate America:

"Disabled and elderly people are not responsible for being handicapped, but they are responsible for becoming rehabilitated. It is not their fault the barriers exist, but it is their fault if they do not surmount them. To adopt Jesse Jackson's words, they are not responsible for being down, but they are responsible for getting up."

Frank Bowe has written a thoughtful and persuasive book. It should be on the shelf of everyone who is concerned with the problems, and the futures, of disabled and elderly people.

Bowe himself is in a unique position to help bring about the changes he so forcefully recommends. As the director of the American Coalition of Citizens with Disabilities (ACCD), he has already effected close working ties with the National Council on the Aging. He has offered a plan for the 80's, and a challenge to everyone concerned with elderly and disabled people.

Rehabilitating America: Toward Independence for Disabled and Elderly People, Frank Bowe. (Harper & Rowe, Publishers, New York, 1980.) 190 pages, $10.95.

—Robert H. Ruffner

Mr. Ruffner is director of Communications for the President's Committee.

A Doctor with a Disability: A Unique Vantage Point

All good physicians possess technical skill. But often, the cutting edge is rapport with the patient. If the physician can penetrate the layers of psychic resistance, he is halfway home. This requires empathy, and an understanding of human suffering—gifts that can't be taught in the classroom. They must come from experience.

Steve Madigan has the experience. He understands what it is like to be a patient. He is paralyzed from the waist down.

Colleagues at the Georgetown University School of Medicine, where Madigan is a senior, say he may have a distinct advantage in treating some patients, because of this empathy.

"People have suggested that to me," he said modestly.

"A neurologist once told me it would be fantastic if I were dealing with patients with specific neurological problems, whether they were from spinal cord injuries, muscular dystrophy or what have you."

No one at Georgetown—not students, hospital staff or patients—ever refers disparagingly to Madigan's disability. It is a tribute to his ability that people in the hospital admire him for what he is becoming, a doctor. What he is, a student in a wheelchair, is now an accepted part of the hospital scene.

During his junior year, Madigan went on rounds and looked in on a woman. When he entered the room, the woman said, "What's a doctor like you doing in a wheelchair?"

On another occasion, Madigan was assisting a neurologist in the operating room. The surgeon liked the way the student had handled himself on a previous case, and suggested that this time Madigan "scrub in," meaning to cut, sew and tie. When the operation was successfully completed, the neurologist turned to him and exclaimed, "I didn't believe it. I've seen it. And now I believe it!"

Steve Madigan has made believers out of a lot of people. His performance in medical school has been outstanding. In the fast-paced medical world, which places a premium on physical endurance and emotional fortitude, Madigan is proving himself the equal to anyone. Hopefully, other handicapped students will follow him, and meet similar challenges with equal grace.

Madigan, an engaging young man of 27, will graduate with an M.D. this year. He will join the ranks of a select group, the very few physicians in the United States with a major paralysis.

Easter evening, 1975. An accident reduced the athletic and powerfully built native of Portland, Maine, to a shadow of his former self. Four fractures—in the left leg, left arm, right clavicle and a fracture of the lower thoracic spine. Paralysis, he was told, would be permanent. Madigan took the news typically in stride.

Severe physical complications during surgery and rehabilitation at Portland Hospital—a pulmonary embolism and urinary tract infection, among others—seemed to unnerve his doctors more than Madigan himself.

When his primary physician asked him how he was bearing up emotionally under the physical strain, Madigan said, "Oh, I'm o.k." "You're not depressed?" asked the surgeon incredulously. "But you have to be, after all you've gone through. It's normal!"

Madigan explains his lack of depression: "It may sound funny, but I saw the accident as a turning point in my life. It set me straight."

The straight and narrow path was not always the case. After college and until 1975, Madigan found himself drifting. His life took numerous wrong turns and wended its way down cul-de-sacs. He segued from one job to another with no real purpose and no specific interest.

For five months he worked as a medical researcher in Hawaii, going there initially because he thought he wanted to go to the University of Hawaii Medical School. Then he worked for seven weeks in Washington, DC, for the Food and Drug Administration in antibiotic analysis. Returning home, he resumed a job that he had held during previous summers, as a surgical technician at Portland Hospital, "which I dearly loved." But that didn't last long and he went on unemployment.

It was about this time that Madigan began voice lessons, thinking that he wanted to become a professional baritone. Six months later he quit that. He took a course in professional clowning and joined a troupe. But the troupe disbanded a few weeks later. Then came the accident which ended the drift.

His quest for the Aesculapian Grail began in earnest after that Easter night, 1975. He had applied to Georgetown three years earlier, but he wasn't admitted until his fourth attempt in 1976. Becoming paralyzed served to renew a languishing interest in medicine, and during his own physical rehabilitation he firmly set his goal of becoming a doctor. Georgetown officials obviously took note.

When Madigan was undergoing physical rehabilitation, he became fascinated with the clinical aspects of his impairment. He suddenly found himself enthralled with human anatomy. As a boy, he used to take apart and put together again all kinds of machines, from cars to instruments he had never seen before. Now he wanted to take that natural mechanical aptitude and apply it toward a career in the healing profession.

Once more he applied to Georgetown, his first choice for medical school, and this time he was accepted. "Georgetown must have been impressed with my determination," he smiled.

Initially, Madigan wanted to become a heart surgeon. "I am fascinated by the vascular system, especially the heart.

It's such a large, mechanical and beautiful organ." During his junior year he took a 14-week rotation in surgery and radiology, compulsory at Georgetown for all third-year students, which opened new vistas for him.

Newly embarking on his last year, he knows he has some tough choices ahead. He's begun to consider doing a residency in either general surgery or radiology. The physical demands, especially in surgery, are heavy, and Madigan knows it. He is also considering doing a residency in psychiatry, although he says he would not do so merely because of his disability.

The subject of his professional future preys on his mind.

"Of course I think about it a lot," he said. "If I take a surgical program where I'm on every other night or every third night, then I think maybe fatigue would hit me quicker than other people.

"I've talked to many people, I've listened to a lot of surgeons, and I think I have to be realistic. To my knowledge there's never been anyone who's gone into surgical residency who's in a wheelchair.

"I think about emergency situations. How would I handle them? If I had a patient who was bleeding or had something where I needed to maneuver around quickly, would that make a difference? What about night calls and fatigue? Am I always going to be medically sound? Are my kidneys going to be in top shape?

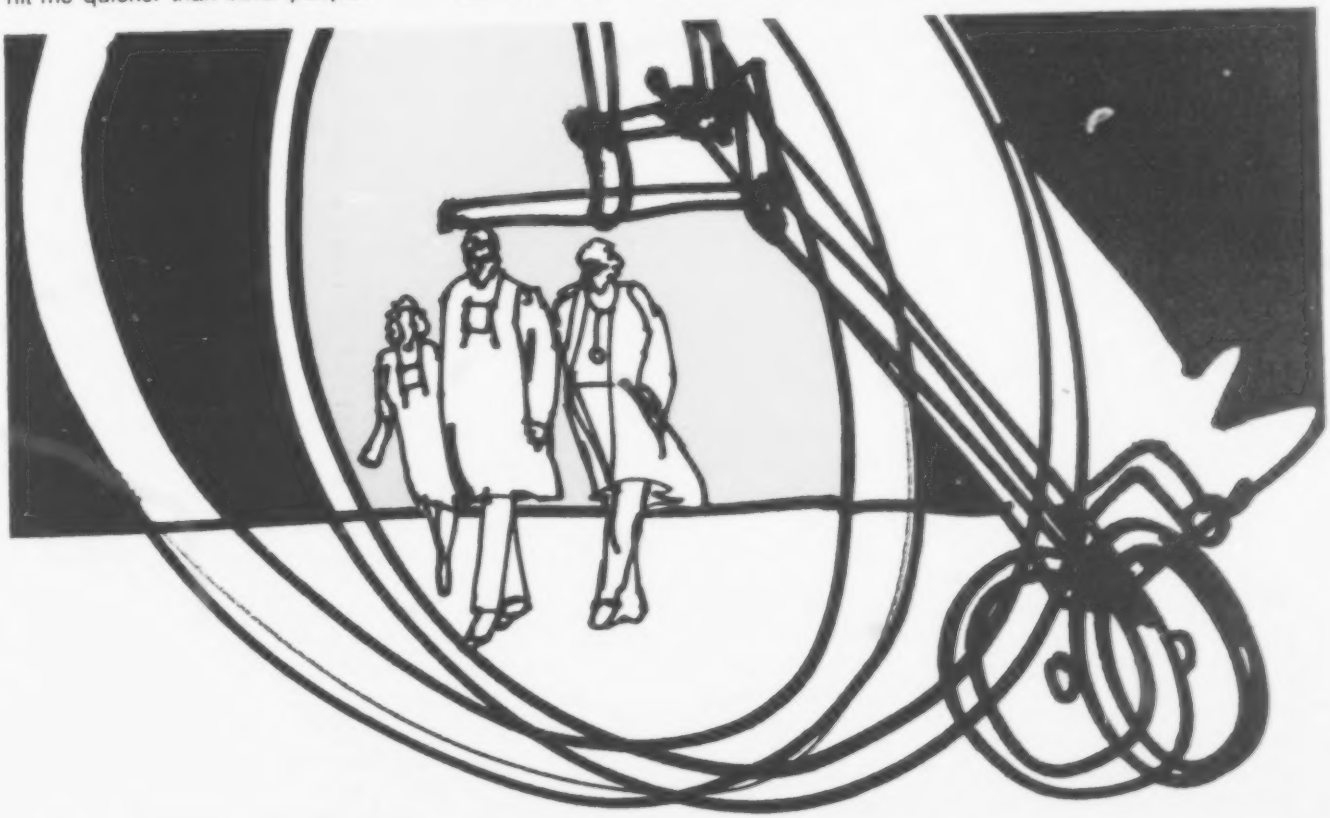
"These are things I've got to think about, not only for the sake of my patients but for my own well-being as a physician."

Madigan won't learn the answers to these questions until he is tested, over a period of time, under the heat of real situations. But, in the meantime, he is making some practical decisions.

He and his friend and mentor, Dr. Thomas Courtney Lee, Georgetown associate professor of surgery, have worked out a special elective in general surgery for him. The experience will enable Madigan to see how he responds under "game conditions."

"I'll make it tough on him," says Lee, who knows that to do anything else would be doing Madigan and the medical profession a disservice. "It won't be easy for him, but if anybody can do it, Steve can."

Lee's comment has special significance for all disabled medical students, not just Madigan. For it reveals this important point: Medical school is a training ground for an exacting career. The standards are necessarily high. The burden of proof falls most heavily on the disabled student, and it is to his benefit that if an error of judgment is to be



made, better it be made on the side of stringency rather than leniency. It is to Madigan's credit that he would not have it any other way.

Dan Turgeon, a classmate at Georgetown, went to high school with Madigan and is a long-time friend: "I don't think any of his friends (in medical school) see Steve as being handicapped. We all do rounds together and he may have to use the elevator, while we go up the stairs, but he soon catches up.

"Steve always wanted to pursue medicine, and his motivation increased after the accident. He didn't give up. He was determined not to let his disability become an obstacle.

"It's his attitude. Steve enters a room with an attitude of control. He's not self-conscious, and patients pick this up. He can perform as well as anybody, and he's been able to do everything the rest of us have done."

It is one thing to check a patient's blood pressure or examine a patient for heart symptoms, but another to perform intricate maneuvers in the operating room. Madigan describes how he adapted during his rotation in heart surgery:

"The table is very high; way up in the air to allow the lines to drain the blood off and pump it back up. Dr. Charles Hufnagel, (he's the chairman), he just said, 'You want to scrub, fine.' He never said, 'How are you going to do it?'

"He saw that I was so interested. I think that's the key. Doctors are people. If you show an interest in what they are doing, they're going to take an interest in you.

"So I said to him, 'Mmmm, this is a great case. I love this.' 'O.k.' he said, 'come on in.'

"So what I did was stack pillows up on my wheelchair, and put the pad that I usually sit on on top, and I was sitting up quite high. I took the two pedals, the swing-out pedals on my chair, completely off. Then I lifted my legs up and propped them on the prominences of the wheelchair and wrapped tape around the outside of my braces. Then I strapped my legs to the prominences, so that they were up and out of the way.

"They moved me up to the table at an angle, so that if the surgeon was standing in a certain spot, my legs were far enough apart so that he was able to move around them.

"It wasn't easy, and it wasn't the most ideal situation, but I did everything. I held retractors, I sewed, I tied."

Madigan had been considering using his mechanical skill to design a special chair that would raise and lower automatically. Now that he is weighing other options, he has put that plan on the back burner.

"I'm still thinking of it," he said, "but it's a slow process. I'm trying to decide what branch of surgery I want to go into. I got hooked up with an ear, nose and throat man, and he suggested I do an elective with him. Ear, nose and throat is all head and neck, nothing below the neck. The operating table has a piston in the center, and the patient's head is way out here, so usually I can wheel in under the head.

"I've done a case with him already and it worked out pretty well."

Dr. Lee, who has already been assisted by Madigan on a number of cases, says Madigan "looks like Mt. Fuji" when he's all propped up and draped. He says if Madigan does decide to do a residency in general surgery, he may possibly use a specially designed table, or use only one operating room. It's not unique in a university complex to use one room, Lee explained.

If the inconveniences of Madigan's impaired mobility turn out to be a problem, it won't be because he didn't exhaust all practical solutions. Lee expressed an equally important ingredient in the medical calculus of his prized student.

"Steve has a tremendous attitude and interest. He asks the right questions, he pursues things.

"I had a guy from Florida who had been shot and was all fouled up. I said, 'Steve, here's your first patient!' Steve pursued it, made calls to Florida, and followed up on every loose end."

Madigan said that on hospital rounds he has met maybe two patients who showed any interest in his wheelchair.

"My experience is that when people are ill they take on a different state of mind. It's almost like a regression back to childhood where the focus of attention is on them. I think patients could care less who you are, or if you have to be carried into the room by eight other people. As long as you're wearing the white coat and a stethoscope, you're the doc.

"The power and image of a physician are just unbelievable. And it hasn't diminished. Even though the public is more informed, when the doctor comes into the room, that is the big moment. So with all the patients I've seen, only one or two brought up the subject of my wheelchair. But then they got right back to their problem."

Madigan has definite views on the challenges facing disabled people. His ideas do not always conform to the majority: "I agree with the recent Supreme Court decision (the *Davis* case, in which a young woman was denied admission to a nursing college on the basis that her hearing defect disqualified her according to the college's program requirements).

"*The Washington Star* wanted me for an interview, but unfortunately I was in Maine and couldn't comment. Because I would have liked to say something about it. When the decision was handed down, everyone was saying, 'Oh, is this going to make it hard for the handicapped?' which is bull!

"The whole thing is attitude. People don't realize, they think that their handicap entitles them to the world. That's the mistake that that deaf girl made, trying to hotshot her way in because she had the marks. If she had said to the school officials, 'Will you let me try and if you don't think I can do it, o.k.,' she might have gotten in.

"A person should not use his handicap as a crutch or a lever to further his educational goals. The law says 'or otherwise qualified.' So you're either qualified or you're not qualified. It's that simple."

Madigan's views, determination, and position as one of only a few severely handicapped medical students certainly qualify him as a unique individual. In his view, "You're either qualified, or you're not. It's that simple."

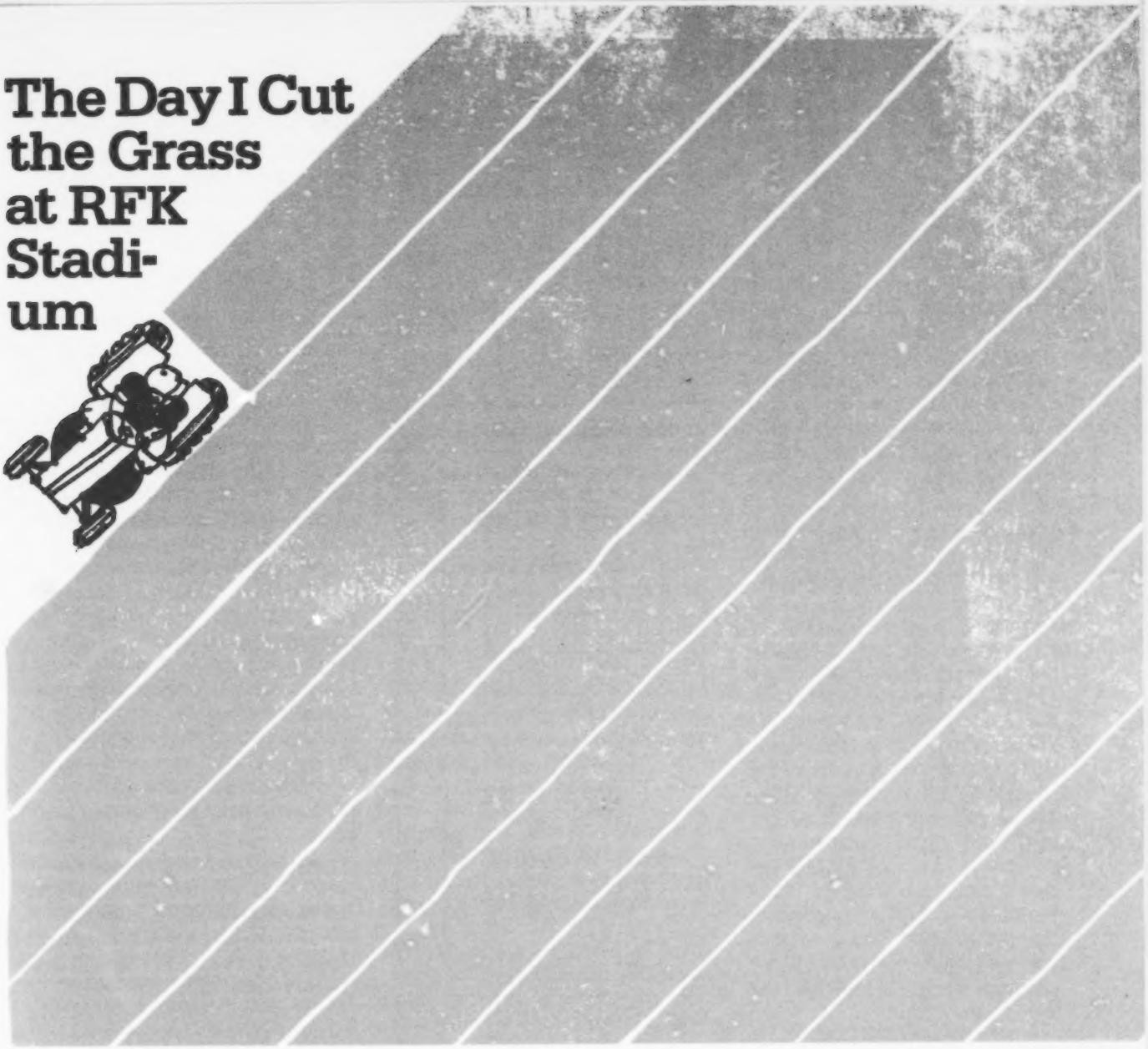
If he sees the law as simple, he certainly knows the future as a doctor will be complex. It will take a unique individual to meet the challenges awaiting him.

It's a big pill to swallow, but Madigan thinks he can manage.

—Alan Nichols

Mr. Nichols is a free-lance writer.

The Day I Cut the Grass at RFK Stadium



Robert F. Kennedy Stadium on the sleepy Anacostia River in Washington, DC, home of the Redskins of football, the Diplomats of soccer, maybe some day of the new Senators of baseball—is surrounded by acres and acres of grass. I know. I cut it.

I was part of a team of 11 mentally retarded men and women who were sent there one summer day to mow all that grass. They are employed by Greenways Grounds Service of Upper Marlboro, Maryland, an unusual place that trains mentally retarded people so that at least some of them can go out into the world and find their own jobs. Those who can't, of course, stay on at Greenways.

Greenways is an offshoot of the Melwood Horticultural Center, also in Upper Marlboro, which has trained hundreds of retarded people in all sorts of horticultural work.

I joined the crew for a day because I wanted to see what effect working close to nature might have on mentally retarded people. The crew members weren't told who I was. Fact is, they didn't try to probe.

I was the new guy on the crew; a little old, but willing. They accepted me for that.

During the day I found . . .

* An extraordinary sense of caring for each other. You might think that grass cutting is a lonely occupation; you push your mower in isolation. It isn't. We were constantly aware of one another, ready to move over to help where needed, without waiting to be asked.
* A pride of work, same as a skilled craftsman might feel on producing an item of quality. We constantly looked back to admire our handiwork, the neatly-cut expanses of green grass.
* An almost mystical transformation. Pushing the roaring lawnmowers, the retarded crew members seemed to cease being retarded as they reached deep within themselves for a sense of adult maturity.
* An effective introduction to almost

any kind of work. Grass cutting teaches interdependence, reliability, sense of achievement, involvement in work—traits all employers look for.

I also found I learned much from them—about caring and cooperating.

IN THE MORNING

I arrived at Greenways early in the morning, before the retarded workers came. They are picked up by minibuses in various parts of Prince Georges County. They come in a little after eight.

Talking to Robie Williams, Greenway's supervisor, and to Henry Hubbard and Lindsay Williams, foremen who accompany the workers on the job, I learned that . . .

- There are 26 people now working at Greenways. About half probably will leave for outside jobs; the rest will stay.
- They do grounds maintenance at 47 different locations in Greater Washington, in crews of five or six. Included are seven public libraries, a swimming club, a convalescent home, a suburban corporation, a bank, several condominiums, a city park. Plus RFK Stadium.
- The workers are called "groundsmen" and "groundswomen," not "clients." Their instructors are called "foremen," just as on a regular job. They proudly wear uniforms; blue jackets and khaki shirts with the Greenways emblem. They now are asking for name tags for their shirts.
- They are all ages, 20 to 50.

THE RIDE OUT

The minibuses arrived. Because RFK Stadium has so much grass, two crews were going out—plus me. Six of us piled into a pickup truck. Joanne sat next to me in the front seat, full figure, bubbling personality. In the back were Joe, self-proclaimed expert lawn edger; Sam, taciturn, with one-word replies to questions; Eddie, in his 50's; Rudy, constant giggler.

8:44

First stop, a tiny general store for post-breakfast refreshments. The choices surprised me: Popcorn; pack of cookies; two ice cream sticks, first one eaten fast so the second wouldn't melt; half-smoked sausage with onions and chili.

Immature choices, I thought. I had selected Spearmint Life Savers which I bolted down three at a time. Was my choice any better?

ARRIVAL

8:50

Arrived at Robert F. Kennedy Stadium. It towered majestically above us as we pulled into a parking lot, so tall your eyes could take in only parts of it at a time. Queen Elizabeth II, riding in a sea of tall grass.

We unloaded the lawnmowers. I climbed up the truck, not knowing what to do. Didn't matter. Everyone else knew exactly what to do. Smoothly, in teams of three, they would lift a mower and hand it down to other teams below. I managed to stay out of the way.

8:58

Four powerful self-propelled Gravely mowers with 40-inch blades; everybody wants them so they are assigned on a rotating basis.

Joanne started hers and shoved it onto the grass; she couldn't wait to begin. She strode easily behind the roaring machine, grass flying high behind her, queen of an empire of grass.

Rudy the giggler and his buddy Jerry, also a giggler, cavorted on the parking lot, laughing and slapping each other and shouting, and carefully avoiding my eyes. Showing off in front of the new guy but pretending not to.

They too were given Gravelys. The moment their hands touched the powerful mowers, the manhood of the mowers seemed to flow from the handles into their arms and through their bodies. Their every step became meaningful. They were in command. No more giggling and mugging. They were men.

I had my choice of leftover mowers. A pull of the cord; surprisingly, it started. I followed the others.

9:02

I was assigned a grassy stretch near the highway skirting the stadium. Jerry and his Gravely headed toward me. Without a word or a gesture, without even looking at me, he moved ahead of me so that I had no choice but to follow him. We cut grass together, in tandem, he in front and me behind, off to the side, in a direction that avoided climbing directly up and down slopes as I had been doing. He, the teacher; me, the pupil. Jerry, former giggler.

9:17

Patsy, barely five feet tall, arched her entire slender body, as she pushed a mower up a hill. Its handle was as tall as she. Up she struggled, pushing not by strength but by sheer will. Her chin jutted out, her eyes burned, sweat rolled down her face. She made it!

MORNING BREAK

10:00

Five of us brought our mowers together, stopped the engines and plopped down on the grass. We lay there, talking idly or not talking at all. Little Patsy proudly proclaimed: "See that hill over there? I cut the whole thing myself. It's my hill. Look at it."

10:10

Rejuvenated, we began again.

Nobody loafs on the job. We all gain a sense of involvement with the grass we cut. The RFK Stadium grounds do not belong to me, yet I felt the pride of ownership in my handiwork. I would stealthily look back to admire the grass I had cut. We all looked back. No reason to loaf when you are involved in your work. Without thinking, I began to cut a stretch of grass that Joanne had mentally staked out for herself. She gave me a look of fire. I backed away.

10:37

That sense of pride was particularly keen in Joe, the lawn edger. Instead of cutting wide swathes of grass like the rest of us, he would edge around trees and shrubs. A perfectionist; not a stray blade of grass remained standing. Edging was more than his job; it was his art.

Later he said to me: "You ever hear of Sammy Davis Jr.? He has lots of talent, don't he? He's a real singer. Well, I have lots of talent too; I'm a real edger. He's a singer, I'm an edger. We both got talent."

RICHARD

10:48

When he pushed the big 40-inch Gravely, it was with all the dignity and grace of a gentleman taking his Russian wolfhound for a stroll in Central Park. Patsy and Joanne glanced at him every chance they got.

I talked with Richard during lunch break. He is barely able to communicate. Small vocabulary, halting speech punctuated with "uh's," far removed from the debonair gentleman who ran the mower.

10:57

I thought about Richard. And about Jerry and Rudy and Patsy and Joanne and Sam and Eddie.

They are nearly inarticulate. Their conversations are largely unfinished sentences and expletives of "right on," "oh, wow," and "yeah yeah." But who needs conversational abilities to cut the grass? This is an occupation where the inability to communicate makes no difference.

11:27

Crew members do not litter. I have seen them walk a block to deposit hamburger wrappings in waste cans. Now I understand why.

The grounds next to the highway that skirts the Stadium are filled with litter. Drivers blithely toss it out the window. Do you know what litter means?

You stop the mower, stoop over, pick up the litter, hold it with one hand, push the mower with the other, move on a few feet, stop the mower, stoop over, pick up the litter, hold it with the other hand, push the mower with your chest, stop the mower, stoop over.

Arms full, you look for a place to deposit all that litter. The waste can is two blocks away. You cut off the engine, start walking. . . .

LUNCHTIME

12:00

We brought our mowers to a central point in the parking lot, shut off the engines, located our lunch bags, sat on a curb under a tree, and ate. The talk was fitful; we were tired. Rudy and Jerry mugged and slapped their thighs; they still avoided my eyes.

Patsy talked about her boyfriends. Eddie talked about the only other job he had ever held, bussing tables at a drive-in restaurant. I listened, scribbling these notes. I leaned against the tree and dozed. Someone shook me; one o'clock.

1:20

A triangular stretch of grass near the Anacostia River. I was cutting from one direction. Eddie, thick neck and beer stomach, was cutting from the opposite direction. Without exchanging a word, each of us took twelve steps, turned in three steps, paused, turned again and crossed each other's path.

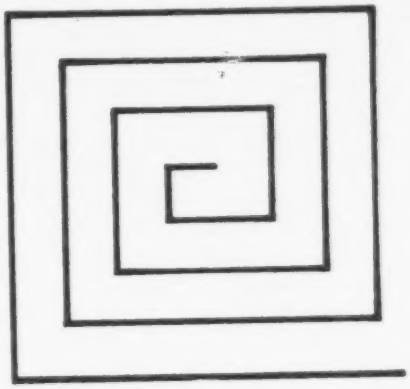
Wordless synchronization. Ballet at RFK.

1:53

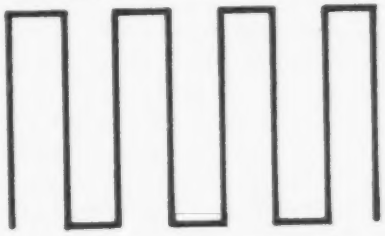
I never saw so much hustle on a job—except for me, pausing now and then to jot these notes on yellow paper. Cutting grass, we are like small businessmen, small entrepreneurs. The areas we cut temporarily belong to us. As we look behind to admire our craftsmanship, we feel the same pride of ownership as the businessman or entrepreneur. Ours for the moment!

2:18

Grass can be cut in one of two ways: Like this, concentric squares fitting inside each other:



or like this, back and forth:



The first way: the closer you come to the smaller inner squares, the faster you go. You look about you at the neatly cut square you are creating and you want it to be complete. You rush.

The second way: back and forth, back and forth, no sudden climax of achievement, no incentive to hurry. I liked the first way.

3:07

Daydreaming, I had become separated from the others. I was cutting a rectangle bounded on one side by a busy street and the other by a parking area. Jerry, my "guardian" for the day, spied me. He tried to push his Gravely across the street. Cars kept coming.

Because he had been so thoughtful of me, I reciprocated. I stepped into the street, raised my hand and brought traffic to a sudden halt. He pushed the Gravely to the other side.

We cut together, he in front, me behind to one side.

3:47

Our foreman waved all of us over to the north side of the Stadium. He wanted to complete a long stretch before quitting time. Eleven mowers all at once, a deep roar reverberating through you. Everyone moved easily back and forth in harmony, except for me. I kept trying to get out of the way of mowers barreling down on me.

Then a hoarse shout. Four o'clock. Quitting time.

DAY'S END

4:06

On the way back to the pickup trucks, we wheeled our mowers past the river entrance of RFK Stadium which had this sign overhead: "Entrance for Handicapped Only." This grass-cutting project, I thought, was another kind of "Entrance for Handicapped Only."

It was an entrance to the regular world of work, courtesy of RFK Stadium, for those whose handicap happens to be mental retardation. It was a pretty wide entrance.

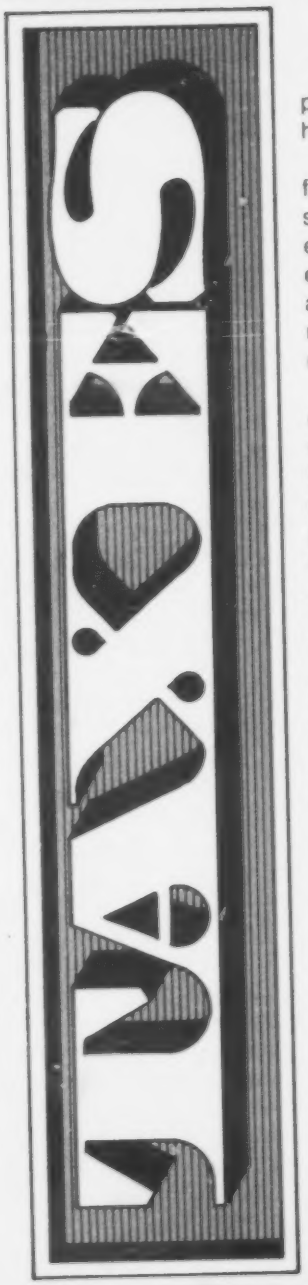
4:29

The ride back to Greenways was quiet. We drove around the Stadium, silently admiring our handiwork. Then out to Maryland. Some of us dozed. There was a kind of tired togetherness in the truck. I felt at one with them; they, I think, with me.

And it was a sad togetherness, a beautiful feeling I knew would never be repeated. Goodbye, my friends.

—Bernard Posner

Mr. Posner is the executive director of the President's Committee.



Jerry Hon, manager of Zytron Corporation, a small electronics firm in Oklahoma, may be typical of employers who have learned to value handicapped employees.

"Frankly, in the past, I shied away from hiring people with disabilities," Hon said recently. "I grew up on a farm in eastern Kansas, got up at 5:30 a.m. everyday, and had always been around able-bodied people. I probably would never have hired Jay Wood if there had not been a financial advantage.

"But, once he came on board, I saw quickly that he's a very good employee, very capable of getting the job done. Now, when I have three applicants, equal in skills and qualifications, this program motivates me to take a handicapped person on board . . . and take advantage of the tax credit."

The program Hon is speaking of is the Targeted Job Tax Credit (TJTC) program, authorized by the Revenue Act of 1978. Private employers can get a tax break if they hire people who would normally experience difficulty in finding a job.

The following groups of people can become employees that enable an employer to take advantage of the targeted job tax credit:

* *Handicapped persons referred from vocational rehabilitation programs or the Veterans Administration;*
* *Young people 18 through 24 who are members of economically disadvantaged families;*
* *Recipients of Supplemental Security Income (SSI);*
* *Vietnam era veterans under 35 who are economically disadvantaged;*
* *Persons who have received general assistance for 30 or more days;*
* *Youths 16 through 18 participating in cooperative education programs; or*
* *Ex-offenders (felons) who are economically disadvantaged and are hired within five years after conviction or prison release.*

What does the TJTC program mean to a disabled person looking for work? If you fall into one of the groups above, it means that an employer can save between $900 and $2,580 the first year you are hired, and between $450 and $1,290 the second year.

Here is the way it works: Employers can claim a tax credit equal to half of the first $6,000 of wages during the disabled employee's first year of work. During the second year, the employer can claim one-quarter of the first $6,000 in wages. An employer's actual savings under this program depend on his or her tax bracket, and the number of employees he or she has.

According to an official at the U.S. Department of Labor, "Small businesses will probably be the main ones to take advantage of this program. Large companies might not care about saving this amount of money. But, for example, if a man and his brother owned a small business with perhaps 10 employees, and could save $8,000 by hiring three employees from the targeted groups, that $8,000 would be a pretty significant sum."

So, a disabled person who is job hunting may find that the tax advantage he or she can bring to an employer is a strong selling point.

In order to claim to be a member of one of the targeted groups, you must be receiving, or have received, vocational

rehabilitation services from your State Vocational Rehabilitation department, or from the Veterans Administration. Here's how to go about getting an eligibility voucher:

First, ask your VR counselor for an eligibility voucher for the TJTC program. If your counselor is not aware of the program, he or she can call the local Job Service or Comprehensive Employment and Training Administration (CETA) offices to get more information.

You can take this voucher with you to job interviews, and explain the program to prospective employers at some point in the interview, stressing the advantages of the program to the employer, and explaining that it has been set up to generate minimal paperwork.

If the employer hires you, he or she needs to complete the following steps:

1. Fill out the voucher (most are short), and send it to the State Employment Security Agency listed on the voucher. The Agency is required by law to issue certification within three days.

2. Keep a record of the number of hours you work.

3. Use the certificate form to claim the tax credit by filing tax form 5884. It's that simple!

If you are not a vocational rehabilitation client, there are some other possibilities for eligibility for the targeted groups. Check and see if you fit into any of the other groups targeted (listed at beginning of story). If so, you may be able to get a voucher from your State Social Security Office, if you receive Supplemental Security Income (SSI).

If you are a student in a cooperative education program, your vocational counselor may be able to help. And if you receive public assistance monies, the office which handles your case may be able to help you. The local Job Service or CETA offices will be able to tell you which agencies can give the vouchers.

The TJTC program has been utilized by many employers. As of the end of November 1979, over 157,000 workers were issued vouchers, and more than 8,000 subsequently obtained jobs. Of these, 4,500 were obtained by disabled people through the VR program.

Jack Bailey, a vocational rehabilitation program specialist, and the national liaison between the Rehabilitation Services Administration and the TJTC program, explains how the TJTC program can help to motivate employers:

"By using money as an incentive, employers are introduced to disabled people. They soon learn that handicapped people are people first, not some negative abstract category.

"You see, traditionally, employers have associated disability with workman's compensation. They usually associate a disability with being 'out on disability,' not with working. Now, employers are being asked to hire people labeled 'disabled.' Until recently, to these employers, disability was absolutely a negative factor—nothing positive.

"But the money provides an initial incentive. This way, many employers who were not aware of the possibility of having disabled people as workers are willing to take a chance. And once they hire these people, they usually find that they are indeed disabled *workers*, not workers who have to be 'out on disability.'"

Robert "Woody" Woodworker, director of the Blind and Disabled Action Center in Ukiah, California, agrees with Bailey that the program is an extra tool to help convince employers to hire handicapped workers. "Sometimes," he says, smiling, "money talks when nothing else can be heard!"

—Dale Brown

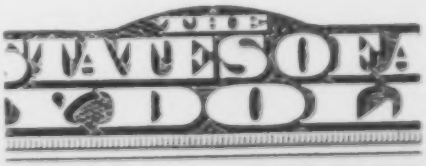
Ms. Brown is on the Communications staff of the President's Committee.

Both employers and workers may be interested in the following resources on the Targeted Job Tax Credit program:

Hire More Workers, Pay Less Taxes . . . describes the TJTC program and other employment tax credits in a clear question and answer format. Available from the U.S. Department of Labor, Employment and Training Administration, Washington, DC 20213. No cost.

New Incentives Benefit Business and Workers . . . describes employment tax credits, including TJTC, in an artistic booklet aimed at private sector employers. Available from the U.S. Department of Labor, Employment and Training Administration, Washington, DC 20213. No cost.

Publication 906 . . . a helpful guide for employers in filling out tax returns. This booklet can be obtained from local offices of the Internal Revenue Service.



Life with Tourette Syndrome

I can vividly remember the conversation that took place between my mother and our family doctor:

"Why does he do these things, doctor?" my mother asked. "He is an intelligent boy. Yet, the way he twitches his nose, contorts his face, and shakes his head so violently makes him look like a crazy one."

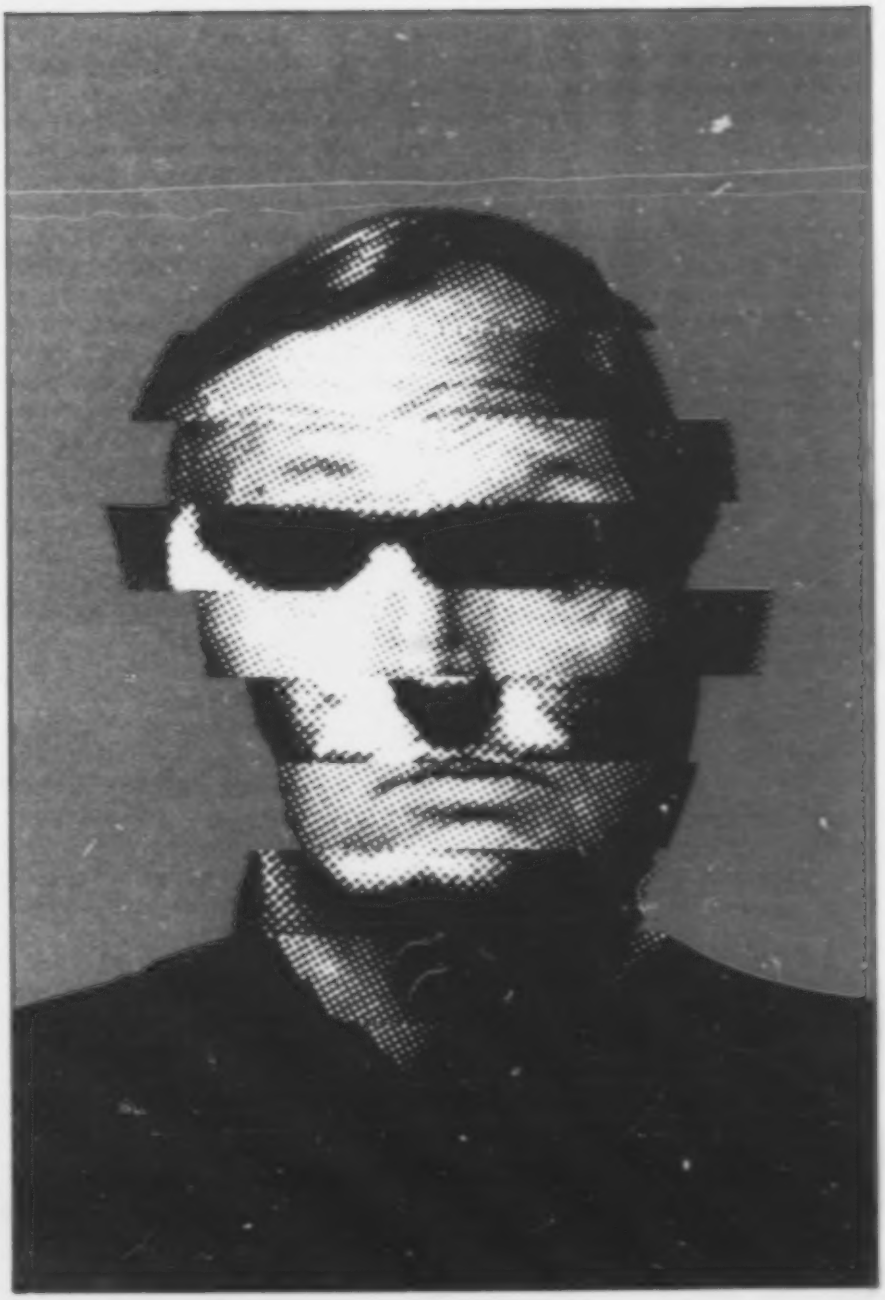
"Stop worrying, Mrs. Werner," the doctor reassured my mother. "He has a childhood habit that is fairly common among teenagers. The best thing you can do is to ignore it, and he will outgrow it."

Thirty-eight years later, I have not outgrown my "childhood habit." But, today my "habit" has a name—Tourette Syndrome. The unique character of this disability has finally been recognized, and its symptoms identified.

Dr. Gilles de la Tourette identified the syndrome back in 1885, but his findings remained buried in some obscure medical journal. Until about 15 years ago, most medical experts remained totally unfamiliar with the syndrome; and to this day, most general practitioners still have never heard of it. As a result, the treatments imposed upon people with Tourette Syndrome by uninformed doctors not only constitute a worthless expense, but the treatments often cause the patient needless agony and torture.

Today, more physicians are familiar with Tourette Syndrome than in the past. This is what they have learned:

Tourette Syndrome usually begins between the ages of 2 and 14, and is characterized by the appearance of tic-like muscular movements. These involuntary movements often first appear in the form of eye twitching and other facial grimaces, head and shoulder jerking, and throat noises.



In the course of time, the symptoms become worse and spread to other parts of the body. Often, original symptoms may disappear and new ones take their place. Involuntary utterances of sounds or words, sometimes obscene, may also occur.

This illness, which so often in the past has been misdiagnosed as an emotional disorder, is now believed to be an organic dysfunction of the central nervous system. Although the exact cause is still unknown, in many cases the symptoms have responded to treatment with medication.

Unfortunately, my symptoms developed during the dark ages of Tourette Syndrome. There was little medical help for me.

The first indication of my problem appeared when I was about 12 years old. I developed a facial tic—I started blinking my eyes, twitching my nose, and generally contorting my mouth and face. (It has always seemed to me that this tic began when I started wearing eyeglasses. But I can't truly say whether this is a significant fact or merely an unrelated coincidence.)

Within six months after the appearance of the tic, my mother took me to visit our family doctor, who diagnosed it as a childhood habit which would disappear if ignored. But neither my parents nor the tic followed the doctor's orders: The tic did not disappear, and my parents could not ignore it.

The tic aggravated my parents, and they frequently lectured me about the need to exercise self-control. These comments, of course, made me feel extremely uncomfortable and guilty, and actually seemed to aggravate the condition.

As the years passed, the condition became worse. The twitches increased in intensity, and other forms of tics appeared. At times I would jerk my arms violently, kick out with my legs, twist my torso convulsively, or throw my head to one side or another.

At age 15 or 16, my voice started to get into the act. I began to make noises which gradually increased in severity and intensity. Often, I would make a sudden explosive outburst, and anybody within hearing distance would jump with fright.

These symptoms did not usually happen at the same time. It was more of an evolutionary process—when a particular "habit" became intolerable to me, to others, or both, a strong effort to repress it usually resulted in another tic taking its place.

By maintaining a storehouse of diverse "habits," I retained a degree of versatility, substituting one symptom for another. This minor blessing enabled me to adapt to varying situations, and continue functioning despite the syndrome.

The severity and intensity of the tics were never constant. When sitting alone and reading, or just daydreaming, there would be no more than some mild twitching. But when another person entered the room, a feeling of tension would engulf me, and the tics would start acting up.

Returning to college caused my situation to deteriorate. Pages of my textbooks were constantly being torn by compulsive streaks of my ballpoint pen or by being impulsively crumpled and ripped out. Today, too, the tics become aggravated when I am under pressure, but are almost nonexistent when I am alone and relaxed.

During my early teens, I preferred to stay at home, completely alone. I did go to school, where I suffered the constant teasing of my peers as any strange and different fellow would. I acquired the nickname "Nose," and I was mocked by many of my schoolmates. Some did restrain themselves because I was one of the better students in my class. These students sought my help with their homework assignments. However, I usually spent my spare time alone.

My mother began to insist that it was not good for me to be alone constantly. She forced me to go out to the community center on Saturday afternoons to mingle with others of my age. I resented it strongly at the time, but I went. I am now convinced that of all the favors that my mother has ever done for me, this was one of the greatest.

For the first few months, I shyly sat alone on the sidelines, browsing through some book or pamphlet. I did not go unnoticed, of course; the syndrome would never allow that. When asked what the trouble was, I merely answered that it was a nervous condition that I could not control, and I was left alone.

Eventually, two fellows befriended me and we are good friends to this day. But the feeling was always the same: I enjoyed the company of these fellows, but I felt more relaxed and at ease when alone.

This mixture of conflicting emotions became even stronger when I began dating. I wanted to go out with girls, to socialize, and to conduct a normal relationship. On the other hand, whenever a girl did accept a date with me, especially more than once, I invariably began wondering what was wrong with her—why would she want to go out with me?

I have often felt that perhaps the greatest liability associated with Tourette Syndrome is the fact that, despite outward appearances, the victim completely retains his sanity. As a result, self-consciousness and embarrassment.

I often felt like crawling into a hole and pretending that the rest of the world didn't really exist. But my mother would not allow that; she kept urging me forward. Eventually, I did succeed in gaining a bit more self-confidence. This in turn, led me to develop a strong resentment against those who showed intolerance, and resentment at being disturbed by my tics. I always remained outwardly friendly and polite, and sincerely apologized to those that I happened to disturb.

At the same time, however, I developed the attitude that I had as much right as anyone else to live in this world, to function, to contribute. I would force myself to face the world; and if any person or group rejected me, I would find others who were wise enough to see through my outer shell. In this way, I pushed myself, not only to mingle among people, but to be the center of attention.

Ironically, I have a pleasant voice (when used normally) and have occasionally served as a cantor in the synagogue. When using my voice normally at full volume, the compulsion for making abnormal sounds is greatly suppressed—the few that escape can be masked fairly successfully. But this situation put a lot of stress on me, despite my ability, so I never sought a full-time position as a cantor.

After high school, I started college. But I dropped out after the first few months. I found classroom situations extremely nerve-wracking.

Since I worked well with my hands, I entered my father's trade as a cutter of ladies' coats. This job called for cloth to be laid out on a cutting table which was six to eight inches high, and then cut according to a pattern by a hand-directed electric cutting machine.

A wrong move could result in the loss of several hundred dollars worth of cloth, the loss of one or more fingers, or both. Nevertheless, I found myself able to redirect my tics so as not to interfere with the work at hand. During my eight years in the garment industry, I never damaged any cloth and, at last count, I still have all my fingers.

After eight years as a cutter, I decided that I wanted a job with a better future. I was a good student in math and science and, though I dreaded the thought of returning to the classroom, I finally forced myself to reenter college to study electrical engineering.

The first day of each semester was the worst: Everyone would stare at me, at first as if I were being a wise guy merely intent upon disturbing the class, and later as if I were some kind of nut. I often returned stares with glares, to make certain that I would not be accused of trying to be funny.

After the first class, I always approached the instructor privately to explain that I had an uncontrollable nervous condition. Final exams also aggravated the syndrome, but by that time people knew me and accepted me. It was a difficult time, but I finished college.

When I began job hunting, I had to explain to prospective employers that I had a nervous condition that I could not control, but that it would not interfere with my work. I occasionally even had to guarantee to pay for any damaged material. But my work always turned out satisfactorily, and only once did I lose a job; a nervous co-worker could not tolerate my explosive vocal outbursts.

Sixteen years ago I began working for my present employer, a major American manufacturer of complex electronic equipment. I hold a senior engineering position, with five engineers reporting to me. People know me, are familiar with my capabilities, and accept me. It took a while, but I finally managed to convince my boss to allow me to speak to customers and to make technical presentations.

In living with Tourette Syndrome, I have found most people are extremely patient and understanding, once the condition becomes familiar to them. Once I prove to people that I can function successfully despite my disability, I am accepted.

But, I would still hesitate to change jobs freely. I have a wife and four children to support. Changing jobs would require me to go through the entire hassle of proving myself all over again. That fear of change will always exist. But if I had to make a change in my life, I feel I would manage.

I have undergone psychotherapy, psychoanalysis, various tranquilizers and skeletal muscular relaxants, a series of electric shock treatments, and a series of nerve-block injections. None of these things offered any relief for the basic problem.

About three years ago, I learned of the existence of the Tourette Syndrome Association. Seeing their full-page advertisement in "U.S. News and World Report," I contacted them, and was soon brought up-to-date on the latest research in the field. I then consulted a neurologist and began treatment with Haloperidol (Haldol).

This drug worked like magic, and provided almost total remission of my symptoms for the first time in my life. But, I was forced to discontinue the drug after several months; it caused me to sink into a severe state of depression. I was suddenly afraid to face the world, afraid to go to work, and afraid of being asked a question that I could not answer. For me, this cure was worse than the disease; and the decision I had to make was painfully clear.

I am taking no medication now, but I am certain that another drug will soon be found. This is part of the work being done by the Tourette Syndrome Association.

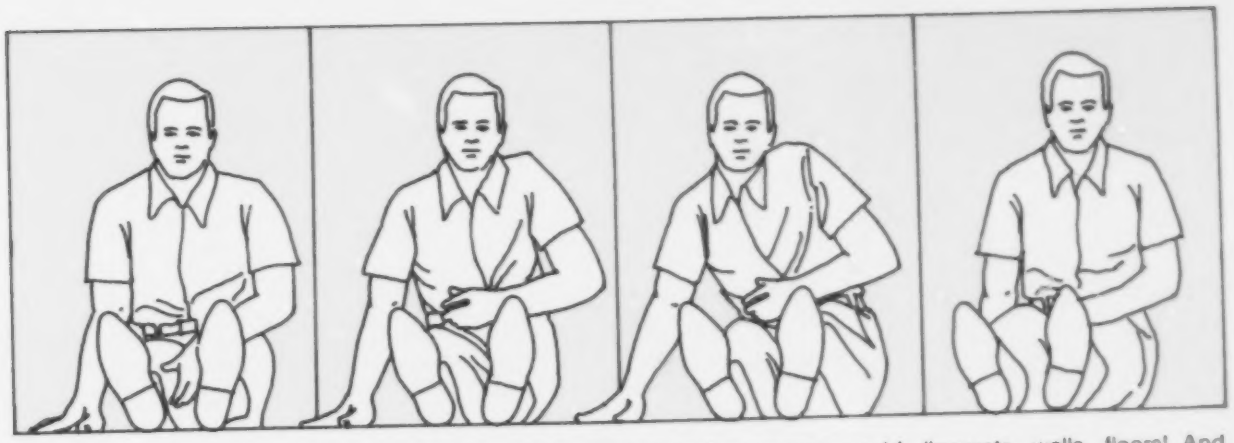
An equally important job of the Association is public information. Through their work, doctors, individuals with Tourette Syndrome and their families, and others are learning the true character of this disability.

Through the Association's efforts, more and more people who are handicapped by this condition are learning how to cope. They are learning not to isolate themselves from society. They are feeling a return of dignity and loss of shame as they attend school, go to work and lead relatively normal lives.

—Ira Werner

Mr. Werner (not his real name) has Tourette Syndrome. He asked that his name be changed to protect his anonymity. For further information, contact: Tourette Syndrome Association, 4240 Bell Boulevard, Bayside, NY 11361.

The Art of Squaddling



My buddy, Bernie Posner, of the PCEH wrote a piece for "Disabled USA" some months ago in which "squaddling" figured prominently. Squaddling is the method of moving about on a floor or the ground by maneuvering the haunches and dragging the feet.

In the article he mentioned a girl in the Israeli hills who lived in a cabin with her mother, and was able to get about to eat, sit in the sun, and go to sleep on a floor mat by squaddling.

He seemed to think that this was the best she could do, and apparently he admired her for it.

I was fascinated because I had never seen or heard the word "squaddling." However, with a severe disability early in life and a wheelchair user for many years, squaddling has been a major means of getting to where I want to go and doing what I think has to be done. And to hell with appearances or can't-doisms!

When I was attending the University of Chicago, I learned that by crossing the Midway I could save two blocks to the transit line. The Midway is an expanse of grass separating the campus; one can go down a 20-foot hill, across a section of grass, and up the opposite embankment. I walked with a cane, and naturally it wasn't that easy.

I would sit at the top of the hill, pretending to be reading as a dozen or so other students were doing. Slowly, I would move down the hill, about a foot at a time, pushing my ankles in front of me. When I got to the bottom, I would stand up and walk across the expanse of grass to the up hill. I would sit at its base, read a page, move up a foot, read a page, and get to the top eventually.

Come to think of it now, squaddling has been a much more serious method of getting about. My wife and I built an apartment building, from blueprints, foundation, and brickwork up. When rental time came, I was sitting in a wheelchair with a fractured leg. The first tenant called to say that he wanted to see the premises at two o'clock.

"You've got to come over here," said my wife, tearfully, "I've never rented out an apartment before."

The apartment was in an English basement, seven steps down. I slipped out of my wheelchair to the top step, squaddled down a step at a time, and got back into the wheelchair. The couple took the apartment, and the next 100 rentals have been much easier.

But sometimes, maintenance hasn't been easy. Or rather, it has been typical. We sold our first apartment building, and bought one in Florida, where neither tenants nor workers are dependable. One tenant was a former cab driver who spent much of his retirement actually fishing. He gave us fresh fish often, a rarity in this fisherman's paradise. When he died suddenly, I felt sorry for his widow and gave her back their deposit so she could rejoin her family up north.

Then came the time to rent out their apartment. It was four steps up, and I had never been in it. My wife went in and promptly came out, crying.

"They have ruined everything," she said, "carpets, walls, floors! And you gave her back her deposit!"

"How could they ruin floors. . . ."

I slipped out of my wheelchair to the nearest step, and squaddled through the door and the rooms. The carpets did smell odd! Apparently, the cats who had lived there, too, had never heard of litter boxes.

"We'll throw the carpets away and get new ones," I said. "And it looks as though we'll have to replace the kitchen floor."

"And you gave her back her deposit!"

I thought of our beautiful cork floor up north, and the many times I had mopped it by sitting on the floor and squaddling from section to section.

"How about a bucket of soapy water?"

My wife thought that the best way to clean up the place was to sit on the sofa and cry—and throw the deposit bit at me. But eventually she got the bucket of soapy water. I ended up with a sore fanny and leg spasms, but a perfectly clean and unruined kitchen floor emerged. That able-bodied couple simply hadn't mopped it once in their four years of living there!

Just sitting there and doing nothing because one can move about only by dragging the feet on the floor? That isn't Yankee ingenuity! But I am grateful to Bernie Posner for putting a word on what I (and undoubtedly thousands of others) have been doing for years.

—Arthur McBee

Mr. McBee is a free-lance writer . . . and a landlord!

The Chairman's Column

"SAME FACE, NEW SOUND" . . . is the title of a new booklet published by the National Easter Seal Society. The publication contains information for laryngectomees, families, and friends. Written by C. Richard Dean and Barbara I. Moidel, the booklet describes how patients learn to speak again, and shares other common problems of laryngectomees in resuming the activities of daily living, including sleeping, eating, bathing, and even sneezing and laughing.

The authors emphasize the crucial role of families and friends in adjustment to the new condition. Understanding, encouragement, and optimism will go far, they say, to restore the patient to a productive life.

"Same Face, New Sound" is based on a survey of nearly 300 laryngectomees and their spouses in Midwestern and Eastern States, as well as on material published in books and professional journals. It contains a list of aids and equipment, as well as sources for additional help and information. To order, write: National Easter Seal Society, 2023 W. Ogden Avenue, Chicago, IL 60612. (312) 243-8400. Price: 75¢ plus 25¢ for postage and handling. Discounts are available for bulk orders.

FILM CATALOGUE . . . Rehabfilm, an audio-visual library that specializes in films and videotapes on disabled people, just released its revised and expanded 1980-81 catalogue. The Rehabfilm rental collection, built up over the last five years, contains films from 12 countries on subjects ranging from physical therapy, orthopedics, prosthetics, and pediatric diagnosis, to employment, recreation, barrier-free design, sexuality, special education, and many other subjects of interest to professionals and laymen alike.

To obtain a catalogue, write: Catalogue, C1, Rehabfilm, 20 West 40th Street, New York, NY 10018. (212) 869-0460.

BARRIERS . . . A new booklet, recently published by the Physical Plant of Gallaudet College, has an innovative approach to the kinds of environmental modifications that can help deaf and hearing impaired persons overcome barriers.

The 13-page booklet, "Breaking Through the Deafness Barrier," explains the importance of visual and acoustic factors in the environment, and has design guidelines on communication devices, lighting, warning systems, visual cues, and reduction of background noise and other topics. To order, write: Thomas A. Lillis, Director, Physical Plant, Gallaudet College, Kendall Green, Washington, DC 20002. Price: Individual copies free; bulk orders are 50¢ per copy.

NEW RESOURCE . . . *Citizen Advocacy Resources*, an annotated list of nearly 500 resource materials and organizations, was published in September, 1979 by The Research and Training Center in Mental Retardation at Texas Tech University.

The resource list was compiled to assist volunteers, parents, consumers, and other advocates in identifying information and volunteer training materials on principles of advocacy, developmental disabilities, rights and benefits of disabled people, administration of volunteer programs, community living, and access.

The book also identifies national and statewide organizations serving developmentally disabled people, State protection and advocacy agencies, and periodicals with developmental disabilities or advocacy as their focus.

Items include materials published by commercial and academic publishers, as well as many materials produced by local advocacy programs. Title, date of publication, length, author, cost, and publisher's address are provided for each item.

Compilation of the booklet was supported by a Grant of National Significance from the Bureau of Developmental Disabilities in the Rehabilitation Services Administration. Copies are available for $3.00 (includes postage) from: The Research and Training Center in Mental Retardation, Box 4510, Texas Tech University, Lubbock, TX 79409. (806) 742-3131.

NEW OFFICES . . . The new address and phone number for National Center for a Barrier Free Environment (formerly located on the Gallaudet College Campus) are: National Center for a Barrier Free Environment, Suite 1006, 1140 Connecticut Avenue, N.W., Washington, DC 20036. (202) 466-6896 (both Voice and TTY).

INVENTORY LIST . . . Vision Foundation, Inc., has just updated and reprinted its large print Inventory List. This 14-page inventory carries over 100 items, most of them free, from around the country.

Materials include sample magazines, brochures, cookbooks, catalogs, and other informative resources in print, large print, braille, cassette and disc. Not every item is available in all media.

Single copies of the large print Inventory List are free. Bulk orders are 50¢ each. Cassette copies are $2.00 each. To order, send check for cost of items to: Vision Foundation, Inc., 770 Centre Street, Newton, MA 02158. (617) 965-5877. Massachusetts residents can call toll-free on 1-800-852-3029.

BRAILLE/TACTILE SIGNS . . . Completely new, Seton "three-in-one" signs include braille letters for braille readers, tactile (raised) letters for non-braille readers, and contrasting letters and background for partially sighted or sighted readers.

This new technique in sign construction meets the requirements of Section 504 of the Rehabilitation Act, and proposed new ANSI A117.1 (1977) specifications.

In addition to "stock" wordings and "custom" wordings, the manufacturer offers braille/tactile plates for elevators and elevator control panels.

For more information, request Seton Bulletin SS50/51 from: Seton Name Plate Corporation, 968 Boulevard, New Haven, CT 06505. (203) 772-2520.

AMTRACK NEWS . . . Amtrack has announced a new 25 percent discount for senior citizens and handicapped travelers, with no holiday restrictions, no round trip requirements, and no limits on length of stay.

The new discounts, which took effect January 1, 1980, apply to any trip, at any time, and on any train when the regular one-way coach fare is $40 or more.

William Norman, Amtrack's vice president for marketing, said that the Amtrack plan is intended to reduce the cost of expensive longer trips, as well as to encourage long-distance traveling. Other Amtrack discounts, most of which apply to round-trip journeys, are also available to handicapped and senior citizens.

Federal law defines senior citizens as being 65 or older for the purpose of the discount, and also sets the basis for eligibility for the handicapped discount. A driver's license, birth certificate or other official document showing age will be accepted to qualify for the senior citizens discount. Cards certifying a person as handicapped, such as those issued by government agencies, or organizations representing handicapped persons, or a letter from a physician may be used to receive the handicapped discount.

Amtrack's current services to elderly and handicapped travelers are described in a booklet, *Access Amtrack*, which is available free of charge from: Amtrack Public Affairs, 400 N. Capitol Street, N.W., Washington, DC 20001. (202) 383-3860 (voice). Amtrack's toll-free TTY number is 800-523-6590.

Harold Russell

THE PRESIDENT'S COMMITTEE
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VOL.3 NO.6, 1980

DISABLEDUSA

Disabled People and Sports . . . the Karate *Dojo* . . . Blind People Ski What About Spectating? . . . and a S On One Man's Breakthrough In the Communications Profession .

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DISABLEDUSA

VOL. 3 NO. 6, 1980

Each year, disabled people become more involved in activities that were once reserved exclusively for the able-bodied. In athletic arenas especially, we see the barriers falling. Here, we take a look at these changes, and what they mean to participants and spectators alike.

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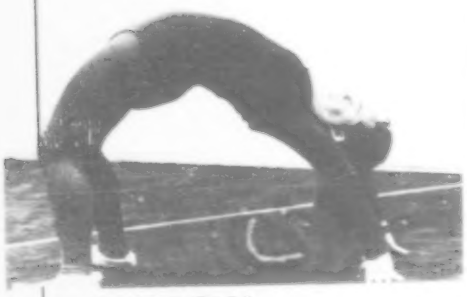

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CHAIRMAN'S COLUMN

PHOTO CREDITS: Pages 7, 8 and 9, Bruce Reedy; pages 10, 11 and 12, Einar Bergh; pages 17, 18, 22, 23 and 24, U.S. Department of Labor.

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DISABLED USA reports progress in opportunities for all handicapped workers, keeps Governors' and Community Committees informed of new ideas and activities, and provides all readers with general information concerning developments in rehabilitation and placement of people with disabilities. In a phrase, Disabled USA presents the case for disabled adults.

The Chairman of the President's Committee on Employment of the Handicapped has determined that the publication of this periodical is necessary in the transaction of the public business required by law of this Agency. Use of funds for printing this periodical has been approved by the Director of the Office of Management and Budget through August 15, 1981.

DISABLED USA encourages the submission of articles for publication by all readers, especially disabled people. Articles should be eight to ten, typewritten, doubled-spaced pages, written in an informal style. We also welcome letters from readers for the RSVP column. (All articles appearing in DISABLED USA may be reprinted with or without credit.)

Karate: Chopping Attitudes

Making his way across the hardwood gymnasium floor, fifteen - year - old Joey took his position in the line facing the judges' table. Falling to his knees, he gave his single crutch to the black-belted figure who had quietly come up beside him. With his teammates, Joey Biner is about to begin the team *kata*.

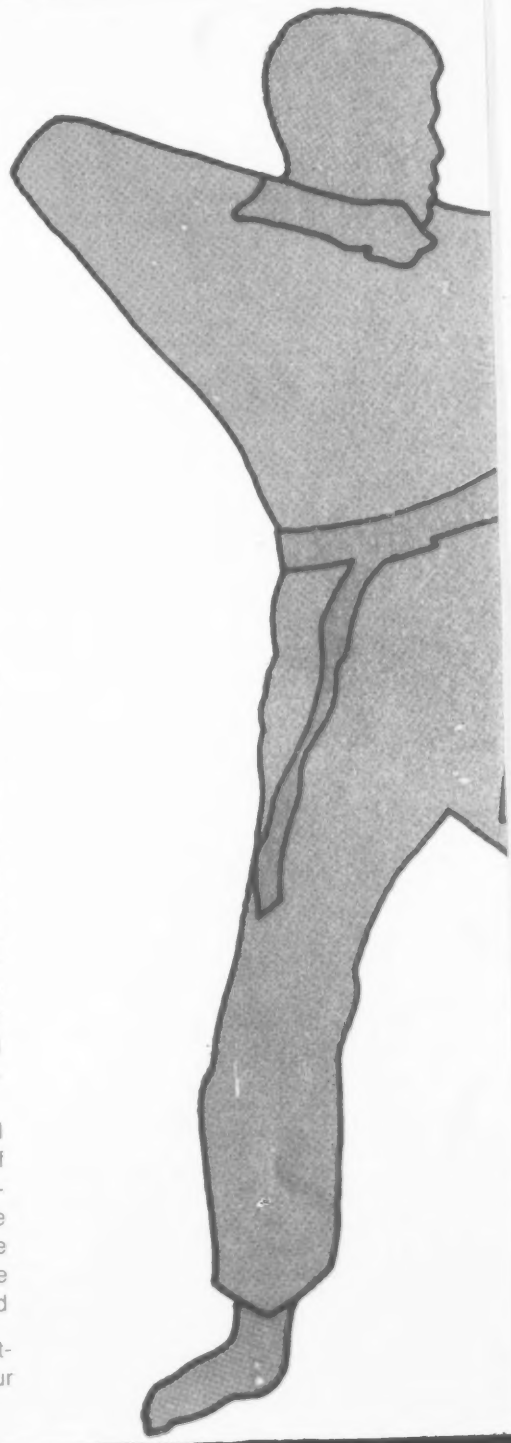
The team *kata* is one of the most interesting and impressive aspects of karate training. A prearranged sequence of basic karate body stances, kicks, hand and arm blocking and punches, kata applies the rigor of self-disciplined practice, to produce an exacting blend of graceful movement, coordination and power.

To an observer the effect seems very much like dance. However, each dance-like movement is executed with the same degree of force likely to be required if the techniques were being used in an actual self-defense situation.

*"Ude uke! Ichi, ni, san, shi . . ."**

Watching Joey move in unison with his teammates, lurching forward now on one knee, arms positioned against attack by an imaginary foe, a familiar image of freedom filled my mind. Being on the floor has meant liberation to many cerebral palsied children and adults, myself included. Freed from the confines of wheelchair, crutches, and uncertain balance, the floor becomes our friend, a platform for uninhibited physical activity and unsurpassed self-expression.

"I became interested in the martial arts when I was watching movies of Bruce Lee," Joey told me later that afternoon, the protective knee pads gone from under his loosely fitting *gi*, the traditional uniform worn during karate training. "I was impressed by his speed



*English translation of Japanese: "Outside forearm block! One, two, three, four . . ."

and the way he moved. I tried to take some martial arts training then, but I was too young. I found I couldn't do anything."

Joey Biner will never have the speed of the famed actor who brought the techniques of oriental fighting to the screen. But as the youngest of seven disabled men and women participating in this special demonstration of self-defense techniques, Joey is now fulfilling part of his dream.

The event was the 18th Annual All American Karate Federation (AAKF) National Championship held recently at California State University, Northridge. Visiting dignitaries, martial arts masters, and men and women interested in karate from throughout the United States and Great Britain were among the participants and spectators for the program of contests and demonstrations marking significance within the ranks of amateur karate.

Proceeds from the event went to the Office of Veterans and Handicapped Student Affairs at the Northridge campus, accenting an underlying theme that "handicapped does not mean helpless." Also present were representatives from area organizations and agencies serving the disabled, and interpreters for the deaf.

Even in my ignorance about the fine points of karate, I was not alone in my appreciation of this particular team *kata*, which drew a standing ovation from the experienced international gathering. As team members remained in poised stillness, waiting for the applause to subside, my gaze fell upon the crutch resting unobtrusively in the team leader's hand. Much drama and effort might have been summoned to signify Joey's transfer to the floor. Instead, all had taken place quietly and unobtrusively.

A karate *dojo* (training hall) may seem a strange environment for mainstreaming to take place. Hollywood has given karate images of brick breaking, high kicking, and fantastic feats of strength and bravery. Added to this is the overconfidence of many high school and college students, whose six-week course in self-defense purports to have prepared them for any attacker. Our popular notions of karate are enough to make many of us wonder what someone in a wheelchair or on crutches can do.

However, for Tony Johnson, chief instructor of the West Valley Karate Club in Canoga Park, California, mainstreaming is a natural outgrowth of his efforts to spread accurate information about karate to the general population. In his capacity as national chairman of the self-defense committee for the AAKF, Johnson became especially concerned when a network news program featured a dangerously misleading demonstration of self-defense for women.

"I felt that the man on the news program was sincere," Johnson recalled, "but unfortunately, the information and skills demonstrated were for advanced students only. Never for the beginner. We must look at the general public as beginning students.

"When you give out information about something which concerns people very much—such as women being attacked or killed—you have to be very careful, because people are going to take that information and try to use it," he continued. "The techniques shown were dangerous, not only because they are likely to be ineffective, but also because use by an untrained person would only serve to anger the attacker, and could mean additional harm, maybe even insuring death, to the victim."

In addition to scheduling appearances on national and local television programs, Johnson began answering an increasing number of requests to speak at schools, businesses and clubs throughout the Los Angeles area. One of these requests came from the local chapter of the California Association of the Physically Handicapped, Inc. (CAPH), a politically-active consumer organization. Although this was his first encounter with the disabled community, Johnson's message to CAPH members was the same as other groups. Karate makes no guarantees and does not produce superheros.

"I cannot tell you how to defend yourself even though I am an instructor in self-defense," he explained as we talked one evening after practice. "The difficult thing about self-defense is that no one knows who the attacker will be, when and where it will happen, or why. You cannot know beforehand whether weapons will be used.

"Therefore, all we can do is to prepare you as best as possible with the practical experience and research

gathered throughout the history of karate. We can say, 'Well, these are the kinds of things that happen most often, and here are the techniques which have been the most successful in these situations.' Ultimately, even with karate, fighting is always a gamble with your life.

"When I tell people that all we can do is prepare them, I am kind of laughing to myself," continued Johnson, a broad smile highlighting his enthusiasm. "I know they are thinking about physical preparation. When I begin talking about character, and how self-defense begins with having the courage to stand up for yourself, and to make decisions in daily life, you should see the look on their faces."

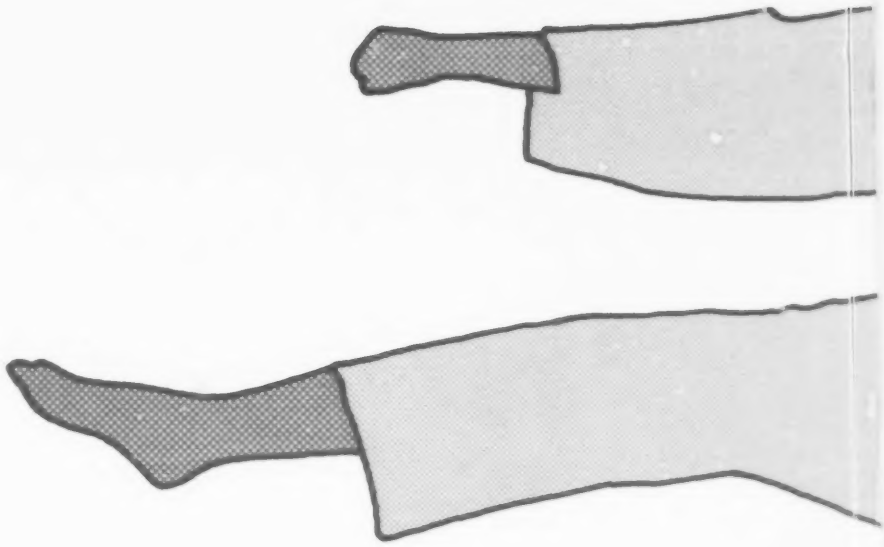
More than a system of physical self-defense, karate is traditionally seen as an invitation and opportunity for continuing self-improvement. The techniques, the actual movements learned in karate, are important only in so far as they encourage students to develop the habit of constant self-evaluation, coupled with a willingness to change. Karate reminds us that, no matter how expert or accomplished one may be, there is always something new to be learned or some aspect of our living which may be better.

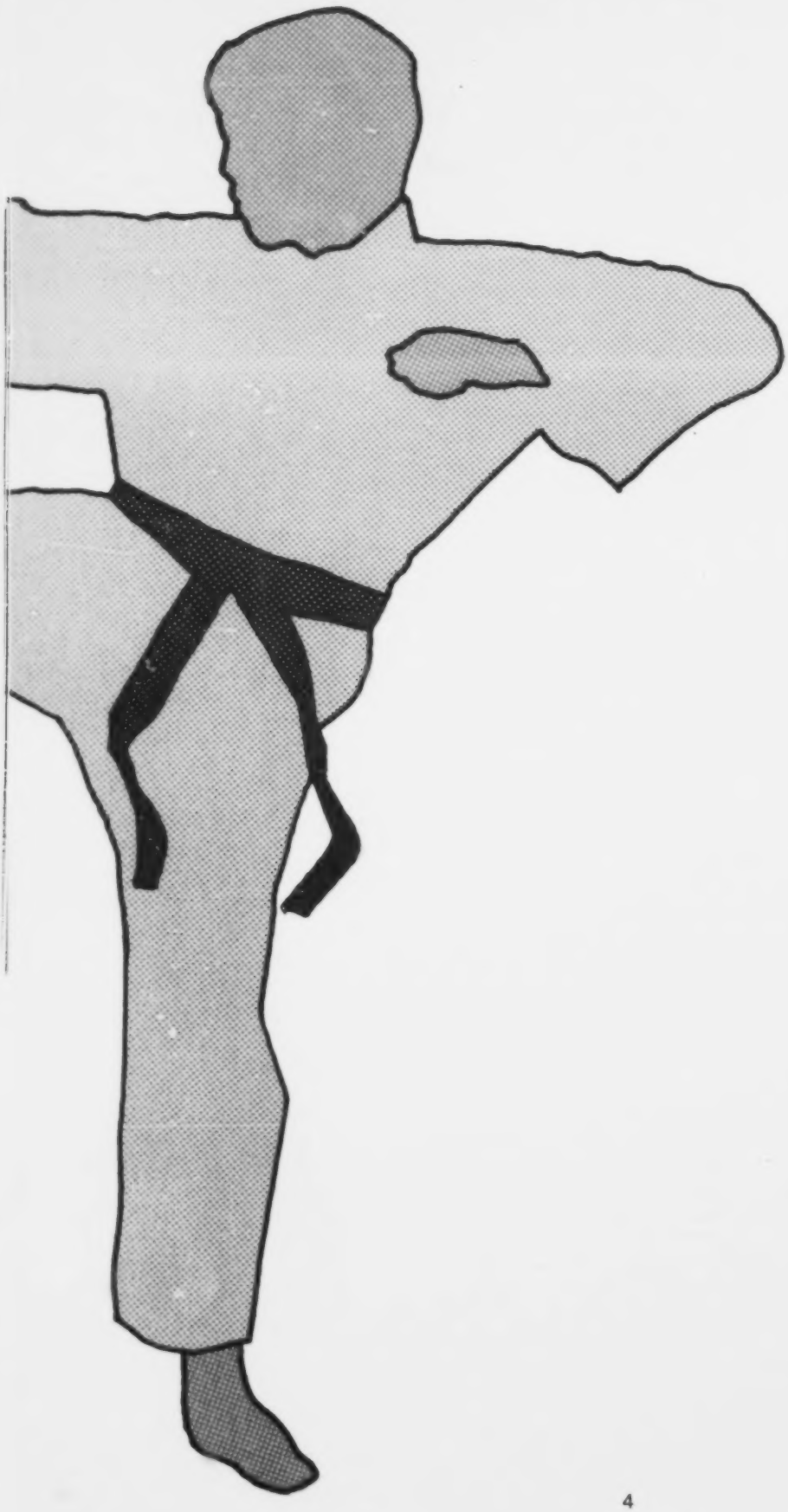
Discipline and self-control are key factors in karate training. In everyday life, emotions exert a powerful influence over people. In stressful situations they can act as a wall, rendering even the most capable person ineffective.

Through karate training, however, students learn to control anger, fear, jealousy and other emotions which can inhibit effective responses in a life-threatening encounter. As this self-control becomes a natural part of the student's character, it helps him or her to responsibly handle other stress-producing situations which arise in the home or on the job.

"The whole purpose of training is to develop a person's character, to constantly seek ways of improving everything we do," the instructor continued. "We do this in karate by learning to control our movements. This gets us in the habit of always looking for ways to improve what we do. These habits are eventually taken out of the *dojo* training session, and applied in daily life.

"We feel in karate that if you take care of the person, checking his or her at-





titude, everything else will take care of itself," added Johnson. "This is why I believe karate can benefit anyone—without restrictions.

"Suppose you are training. Maybe you are having trouble making a good, straight punch because your arm waves from side to side. So what? You are benefiting physically from the exercise, and mentally because you are learning something new. Also, you are learning to control your emotions. This is what is important."

Soon after his appearance before CAPH members, Johnson was asked if he would be willing to teach a self-defense class for the disabled. The instructor readily agreed, imposing one condition. The class would have to be conducted under the supervision of medical professionals trained in rehabilitation.

"Karate says I must understand the person. This means also that if there is some problem or disability, I must understand what is dangerous to that disability and what is not," Johnson explained. "Many of the members were ready to begin training right away, but I had to look out for the possibility of negative consequences."

Bob and Mary Campbell were among the first to participate in the classes, which began at Northridge Hospital in November, 1978. Tony Johnson volunteers his time to teach in this pilot program, which has attracted students with varying handicaps, including spinal cord injuries, birth defects, cerebral palsy and stroke.

"I really became interested," recalls Mary Campbell. "I heard about the program at a CAPH meeting and wanted to try. We went to the hospital class for four or five months. Then Tony decided we were ready to join the able-bodied class here at the *dojo*."

"Tony wanted to try an experiment," Bob spoke up. "He brought us to the *dojo* to see what the reaction would be. And, of course, there were stares and so forth at first, but we were soon assimilated right into the regular class."

The Campbells, who both use wheelchairs, attribute the successful mainstreaming to Johnson's disciplined training technique. Disabled and non-disabled students are treated alike on the *dojo* floor, and criticism falls readily on anyone deserving it. In addition to

trying each exercise and technique they may be able to do, disabled students are expected to attend class regularly to learn to recognize and understand the principles behind kicking, stance training, and other karate movements which may be beyond their particular ability.

"If the class is doing kicking exercises, we don't just sit there," Bob interjected. "We do our arm exercises on our own. Tony does not want us slacking off at any time."

"He's very strict," added Mary. "But the students really respect him for this.

"We each go at our own pace in training," she continued. "Tony can't know our strengths and weaknesses. He shows us what to do, and we try to do it the best we can. Some things I can do better than Bob, and other things he does better than I can. It's no different than if we were on our feet."

"The able-bodied students can attack us in any way they want, with kicks or punches, and from any direction," added Bob. "We have to be ready to defend ourselves by blocking the attack. You watch their eyes and you can tell what they are planning. There are certain blocks that you learn to do automatically."

The couple agree that karate has been worthwhile for them, not only for the purpose of self-defense, but also as a way of breaking barriers between disabled and nondisabled people.

"It really gives you a good feeling to discover you can do some of the same things the able-bodied students do, even if you use a wheelchair," Mary noted. "It has given me self-assurance. I do a lot more things now than I would have tried to do before."

"We have both gained a lot more confidence just in everyday life," added Bob.

The Campbells are right about Tony Johnson. On the *dojo* floor he is a stern and demanding taskmaster. Off the floor he is an eager, personable man whose searching mind is refined by his firm hold on reality. He is not content to accept only the input of rehabilitation professionals. Through study and observation, he has already come to grasp many of the complex processes involved in bringing disabled and nondisabled people together, and the importance of helping those with a handicap outgrow a self-image which somehow marks them as different.

As we talked about the future of his pilot program, I sensed that he would like to bring the special hospital class to an end. For Johnson, the idea of having separate classes for the disabled and nondisabled is silly. Mainstreaming, going beyond individual abilities to address universal human needs, is natural.

Yet, in observing the effects of his experiment and recognizing the needs of individual students, Johnson faces the same frustrations and contradictions which will plague mainstreaming and affirmative action efforts for a long time to come.

"I just realized as I talk with you that I am consciously making decisions about the hospital program that I feel are right," he commented. "For example, if a person comes to the hospital class for the first time, rather than to the *dojo*, this can mean several things. Maybe he does not feel comfortable enough yet to deal with society, except maybe a disabled society. The hospital class is very valuable for these people.

"But there are those who come to the hospital because it's the first thing they hear about. You can tell these people have learned to cope with their disability," he observes. "They know, for example, that if they are in a wheelchair or if something else is different about them, someone is going to look.

"That's exactly what happened when the first disabled students came to the *dojo*. The first session was a disaster—the young people stared, and the adults tried their best not to see. At the end of the class, I encouraged everyone to get acquainted and ask questions. By the third night 'those people' had become Bill, Bob, Mary and so on. That's the night all the talking really began."

Today, new disabled students coming to the West Valley Karate Club *dojo* are both accepted and expected. It has become a familiar sight to see wheelchairs interspersed within rows of upright bodies. My own presence as an unannounced observer aroused nothing more than friendly inquiry as to when I would be joining the class.

In fact, working with disabled students has given Johnson new approaches to general training. Injured able-bodied students are required to continue attending class sessions, and are expected to train in a spare

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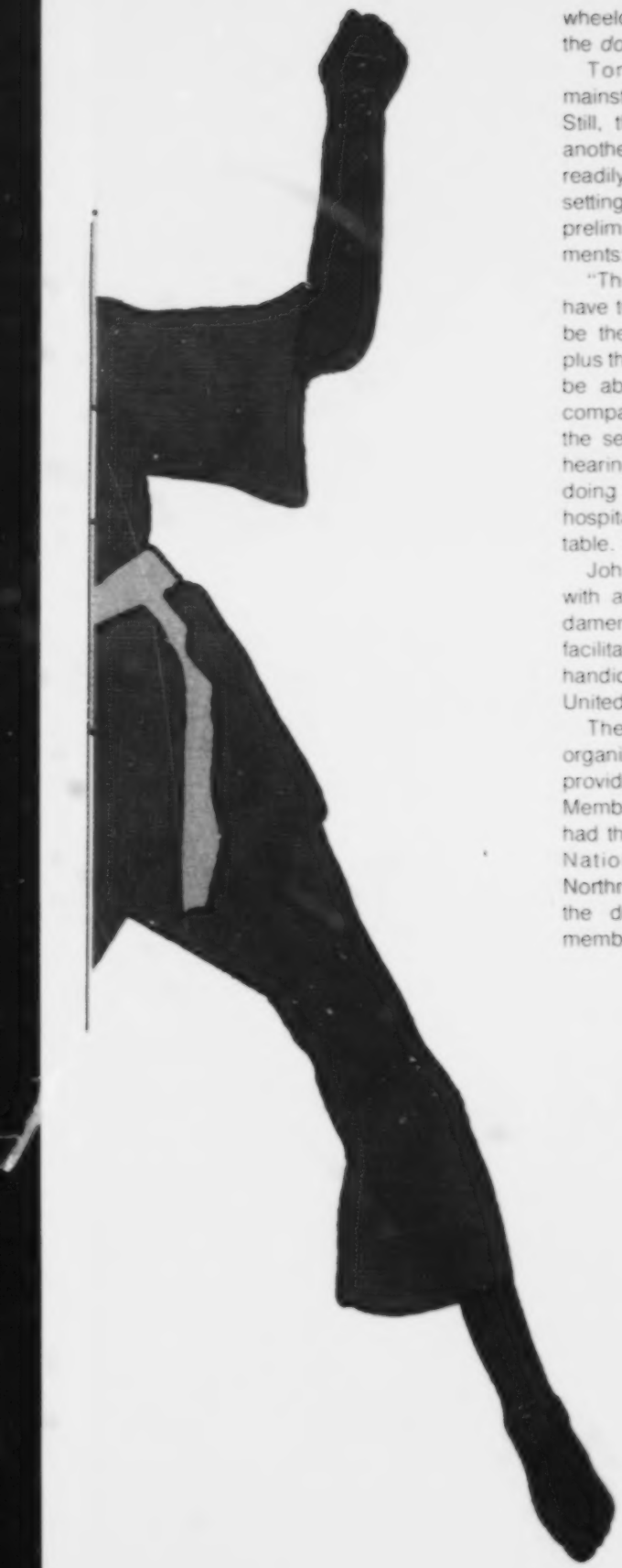


wheelchair Johnson keeps on hand at the *dojo*.

Tony Johnson's experiment in mainstreaming has been a success. Still, the hopeful instructor recognizes another complexity. Even for those readily able to integrate into the *dojo* setting, the hospital class serves a useful preliminary purpose. Johnson comments:

"Those coming to the *dojo* initially have to cope with what they expect will be the reaction of the other students, plus the additional concern of 'How will I be able to perform these techniques compared to everyone else?' But once the session begins, they find they are hearing me say the same words and are doing the same training they did at the hospital. Immediately, they feel comfortable. Some of the concern lessens."

Johnson's basic interests now rest with attempting to put together a fundamental training program which will facilitate the opening of karate classes to handicapped persons throughout the United States.

The AAKF, which is a national organization governing amateur karate, provides a natural channel for this goal. Members of the West Valley Karate Club had this in mind when, as hosts for the National Championships held at Northridge this past Fall, they included the demonstration by disabled club members.

"As long as someone is willing to work with me, I do not care if he or she is on crutches, in a wheelchair or on a gurney," says Johnson. "We'll find something to do. But let's not say that the person on the gurney will be able to do what I can do. Let's be realistic. Let's see things as they are, then just try to work with what we have.

"We need disabled people who will enter training and stick it out," he continued, "and who will help with the development of the program by being honest. This is a learning process on both sides, and if something isn't feeling right I need to be told about it.

"I need to understand what it feels like to be disabled, the frustrations of not being able to, say, cross the street by yourself or tie your shoe. Maybe all your life you have been taken care of," observes the instructor. "Then, all of a sudden, someone is saying 'I'm not going to take care of you. Fight for yourself. Do the training yourself. I don't have time to spend with just one person.'

"I am threatening you and your body reacts—and maybe it does something it has never done before. Perhaps you discover you can do things you didn't think you could do. Maybe you were afraid to do them before. Or more likely, you were never put in the position of having to try.

"There has to be some way to get disabled and nondisabled people together so they can discover they are not that different," stated Johnson with a hint of impatience. "I am hoping that through the training here at the *dojo* . . . I don't know. I just don't know how to get this across to the general public."

Karate is not for everyone. Few persons, disabled and able-bodied alike, have the patience and self-discipline necessary to withstand the rigorous training. Neither will complete mainstreaming happen overnight. For those who are interested, however, Tony Johnson and his students are showing a way.

For information write:
Tony W. Johnson
7041 Eton Avenue
Canoga Park, CA 91303

—Pam Hoye

Ms. Hoye is a free-lance writer.

The Special Olympics

Where do you find such a spirit of helpfulness? Among Special Olympians. I saw this in action during the Fifth International Summer Special Olympics last August, as 3,500 mentally retarded children and adults from each State, U.S. territories, and 20 foreign countries competed at the State University College at Brockport, New York.

Despite their helpfulness, generosity, and caring for one another, the athletes still possess a strong desire to win. As a bus with delegates from Washington, DC, covered the miles to Brockport, the athletes chanted, "V-i-c-t-o-r-y is our cry! La de dah, la de dah," over and over.

"Cheating is virtually unknown, nobody plays out his options, and if somebody falls during a race, his competitors can usually be counted on to stop and lend a hand." (Sports Illustrated, August 13, 1979.)

My niece, Dorita Parsons, had worked hard all summer to perfect her swimming skills. When asked what she thought about as she swam the 25-meter freestyle, she paused, then replied, "I might win!"

The Special Olympics program, which consists of year-round training and participating in contests, games, and meets, is open to all retarded persons, eight years or older. Edgar Mitzel of North Dakota, 63 years old, was thought to be the oldest participant at Brockport.

Generally, athletes have I.Q. scores of 75 or less. Athletes at all ability levels are assigned to competitive divisions based on age and degree of disability. This makes it possible for even athletes in the lowest ability level divisions to advance to the international games, competing with other individuals with the same degree of disability.

To prepare for the international games which are scheduled every four

years, local, chapter, and national games are held annually in many communities. Recreational and athletic, as well as promotional events are planned throughout the year to enhance the program. For example, recently several Special Olympians from the Metropolitan Washington, DC, area demonstrated their skill in the basketball throw during a TV special on the Washington Redskins football team.

Doing well in sports is not the primary aim of the Special Olympics. The leaders, mostly volunteers, encourage trying even more than winning. In the Special Olympics, every athlete is a winner. The athletes often gain in confidence, and in the development of positive self-images after successful experiences in sports.

"Not in the clamor of the crowded street,
Not in the shouts and plaudits of the throng,
But in ourselves, are triumph and defeat."

—Longfellow

Sometimes, also, they can transfer these new characteristics to home, school and work situations. Complacent and placid, Dorita, since participating in the games, has been more assertive.

The Fifth International Special Olympics had all the pomp and pageantry of the regular Olympics. It opened with the lighting of the Olympic torch, and there were similarities in the other activities, such as the closing ceremonies, awards presentations, and a variety of clinics in sports and games.

And yet, the Special Olympics *was* different and special. The college stadium overflowed with more than 10,000 people at the opening ceremony. No tension emanated from the athletes. Their many-colored uniforms resembled a kaleidoscope as they marched around the stadium, waving to the crowds.

Throughout the four-day event, celebrities such as boxer Muhammad Ali, 1960 Olympic decathlon winner Rafer Johnson, and actress Sally Struthers, talked to, worked out with,

Blind Skiers: A New Challenge

"Skiing as a pair
They glide amid
stately pines
Only one can see . . ."

Thus reads a poster for an international meet of "Ski for Light," an innovative program of cross-country skiing and ski touring for visually impaired and other physically handicapped people. In 1979, the annual meet took place in Squaw Valley, California. This year it was held in Traverse City, Michigan.

Each year, over 100 disabled skiers, along with an equal number of guides, meet for a week of skiing and socializing. Generally, skiers range in age from 18-67. Most are visually impaired, although there are also some who are deaf-blind, and others who have mobility problems.

Ski for Light teaches cross-country skiing, rather than Alpine skiing, where the skier goes directly downhill. In cross-country skiing, a weighted sled makes two tracks which are followed by skiers. The cross-country skier provides his or her own propulsion uphill or on level ground. The equipment used in cross-country skiing is also lighter and more comfortable than that used by Alpine skiers.

Skiers who are paraplegics, or who have other mobility problems, ski in special sleds called "pulks," which were developed by Dr. Vidar Johnson of Norway. A pulk looks somewhat like a kayak, and the skier sits in the rear of the vehicle, comfortably cushioned on a sleeping bag inside a shell of fiberglass which has a canvas cover. The vehicle has runners and can be steered. Pulk skiers also use shorter poles, suitable for a person sitting down.

In Ski for Light meets, two sets of tracks are laid out parallel rather than the usual one set. This way, the blind skier uses one set of tracks, and the guide or instructor can ski beside him or her on the other set.

In Traverse City, training took place on a flat, snowy meadow in front of the Ranch Rudolph hotel. Over 100 pairs of skiers were scattered over the field. People wearing skis for the first time were obviously both nervous and excited. Commented Keiko Namekata, a rehabilitation teacher from Chicago, "At first my legs just didn't go the way I walked! I felt kind of locked in. But, like almost everyone else, I soon learned the relaxed glide of cross-country skiing."

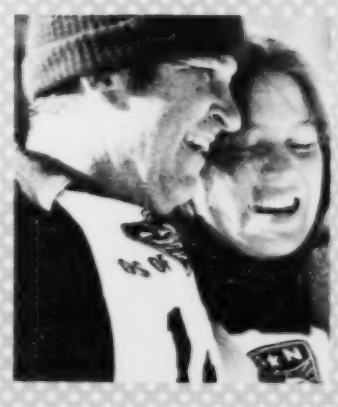
The scene was like a ski class anywhere—with one exception. Bud Keith, an equal opportunity specialist for the federal government and a member of the board of directors of Ski for Light, pointed out: "A blind person can't see the instructor. So if something is hard to explain verbally, the instructor has to manipulate the blind person's limbs, or assume the stance himself and let the blind person touch him."

After a few hours of training, people started to ski alongside the Bordman River through a magnificent wooded area. The trail was hilly, but the soft sounds of the river, and the aromatic pine trees made the effort well worth it.

"When I first started skiing," said one Ski for Light participant, "I thought it was great. I loved the feeling of moving so smoothly over the snow. The soft sounds of the river . . . the smell of the pine trees . . . the swish of the skis through the snow . . . It was heaven."

Bud Keith commented, "Skiing is different for blind people because it's hard to judge your speed. You may think you're moving fast and you're not moving at all. The snow is smooth and you're not touching anything. If you're going with the wind, you may be moving fast and feel like you're not moving."

Floyd Johnson, a painter and the owner of an art gallery, began skiing before his eyes began to fail him. "The main thing that's changed since I became legally blind is that I lack the knowledge of what's coming up. I find the preset tracks really helpful. And of course, having a guide alongside you



really takes the fear away. Anyone who has skied for awhile can be a guide. It's just a question of getting the verbal communication going, of learning what the person can see, if they're partially sighted like me.

"The only help I need is to be told about a turn around ten feet ahead. Otherwise, when I get to it, it's rather startling to have the tracks suddenly turn!"

Keith elaborated: "You need good communications with your sighted guide. He can't say 'Well, there's a turn up ahead!' You don't know if it's left or right. He has to say, 'sharp right turn,' or 'short steep uphill!' "

"I had a terrific guide," said Keiko Namekata. "He was a big man, which was great. When I fell, he could grab me. He made me do everything I was supposed to do, which was good, because sometimes sighted people tend to over-help blind people. He let me go at my own pace. He was very patient. I could trust him."

Ski for Light has an almost perfect safety record. According to Keith, "In the last five years, we've had one dislocated shoulder, one torn knee cartilage, and one broken toe. That's five years, twenty-five days, 550 skiers, and I don't even know how many miles."

The guides have as much fun as the skiers. Brit Peterson, a professional indexer at the National Geographic Society, describes her experience as a guide at Squaw Valley, California:

"First I taught David Grimes. He was 22 years old, a jogger and an ice skater. Within two days, he had learned so well, I was exhausted. I didn't want to be his guide during the race which came at the end of the week, because I was afraid I'd hold him back. He said he wanted to race with me, but I said 'David, I'll never keep up. Your legs are too long. I'm 5'3" and you're 6'2".' So I got another guide to ski with David for the race. He came in first place among the blind men over the age of 35.

"I also worked with Maxine Schramm. She was 65 years old, one of the oldest skiers. When she came, she didn't know anything about skiing. I got her going into slow, sure skiing. She completed the five kilometer race. We took a long time. They sent somebody back over the trail to look for us, we took so long! But she completed it. I was happy to teach her and really enjoyed it. The year before she had gone down the Colorado River in a raft. Maxine didn't like skiing that well, so she won't come back. But she wanted to try and she tried."

At Ski for Light meets the social activities are as enjoyable as the ski touring. At Ranch Rudolph, the evening program included ice skating, roller skating, a talent show, and an awards banquet.

The program gives blind and sighted people a chance to interact on the basis of a common interest, not based on disability. According to Keith, "many blind people say that it is the first time they've experienced such warmth and comaderie with sighted people. At the end of the week, the atmosphere is truly rare. We've created magic."

Guide Brit Peterson got involved with Ski for Light through her work with the Sons of Norway, the largest organization of Americans and Canadians of Norweigan descent. Sons of Norway established Ski for Light based upon a similar program in Norway. It has over 100,000 members and has adopted Ski for Light as an official outreach project. Members who enjoy skiing are encouraged to volunteer as guides, whether during official events, or informally with blind people in their area.

Ski for Light is a corporation, and according to Einar Bergh, general manager of Public Relations, one-third of the 27-member board of directors are handicapped. Disabled people have been gradually taking over leadership responsibility in the program. George Wurtzel, the chairperson for the 1980 Ski for Light international meet, is visually impaired, and handicapped people served on the three major committees; Program, Transportation, and Ways and Means.

The yearly international meets are not the only opportunity for visually-impaired people to enjoy skiing. Ski for Light also promotes regional meets. They are usually organized by visually-impaired people and guides who formerly participated in the international meets. Local Sons of Norway clubs often participate too.

In Traverse City, Bud Keith gave a talk on how to organize regional meets. They are held all over the country, and large ones have been recently held in Deer Mountain, South Dakota; Sugarbush, New Hampshire; and Somerset, Pennsylvania.

According to Keith, the regionals and nationals provide structured situations, but the main purpose of Ski for Light is to train individuals to ski wherever and whenever they want.

Keiko Namekata has the last word: "I like skiing because it's a sport that you can do with other people. It's a family activity. My husband skis. We're starting my young daughter on it now. Besides, when you live in Chicago, what do you do in the winter?

"Ski, of course!"

—Dale Brown

Ms. Brown is on the Communications staff of the President's Committee.

Sometimes you take the "roach approach." Sometimes you just take what is available. And sometimes you raise a bit of a fuss, and wheels start spinning in your favor. Ideally, you should be able to just go in there and enjoy.

The handicapped sports fan wants to get away from his TV set and out into the cheering crowds where the real fun is. Yet, sports arenas are notorious for their inaccessibility, sports merchants for their insensitivity, and rules and regulations often flout the law.

Former Villanova basketball star, Bob Sexton, now a Capital City Hustler of Raleigh, North Carolina's fine wheelchair team, explains the "roach approach":

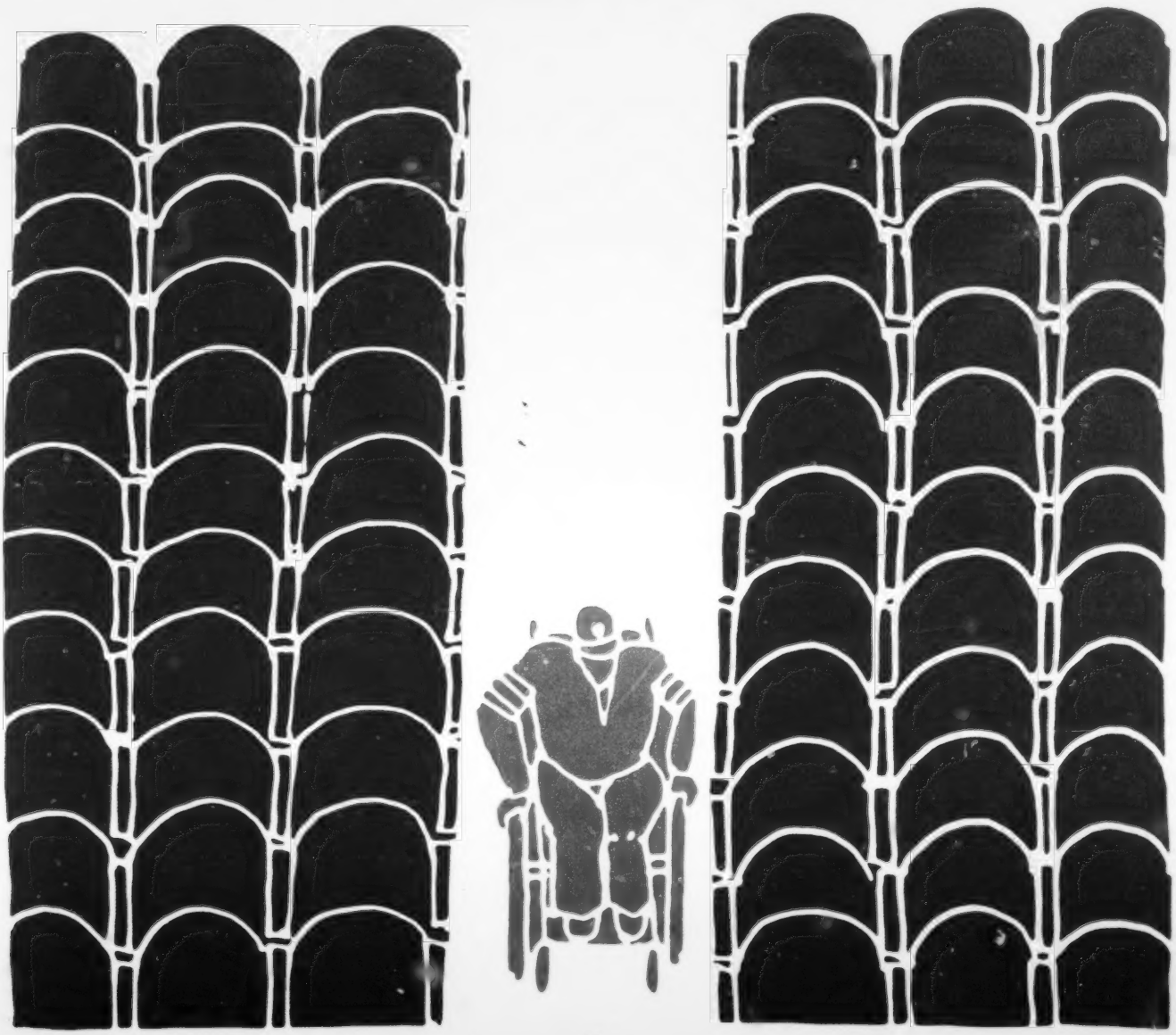
"What I mean by this is that we go in the back doors, up the back elevators, sneak in on the floor, get kicked out at half-time, and then when play starts again, we go through the whole thing again."

Nobody likes being a roach, but when basketball arenas are run the way many of them are, it's the only way a person using a wheelchair can see the game.

Sexton is a passionate basketball fan as well as player, and recently he attended a little homecoming party in Philadelphia with his father and sister-in-law. They bought third row, ($9.00) seats in Philadelphia's Spectrum. It was a special occasion—the Boston Celtics vs the Philadelphia Seventy-Sixers.

Up rolled Sexton, only to be told to go to the top tier, where handicapped people were allotted seats near a fire exit. It seems Sexton was a fire hazard in the $9.00 seats, and was being ordered to a $6.00 seat.

What About Spectators?



"Well, I did what I was told, but I couldn't see a thing," he said. "Remember, this was on the last row of the upper deck. I snuck down a freight elevator, went to where Dad and my sister-in-law were sitting, parked my wheelchair, and they helped me up three steps to my seat. I was enjoying the game when this official-looking guy came back and told me I'd have to sit on the top row."

Rather than make a big fuss, Sexton returned to the top tier.

"Well, Spectrum is accessible, I guess, if you want to sit way up there," he said. "It's accessible, I guess, if you bring binoculars."

Back home, he finds sports officials very aware of what's discrimination and what's not, but this state of affairs didn't come easily. Dr. John Fritz, a paraplegic, set sports people at North Carolina State University in Raleigh on their collective ears six years ago, and made things happen.

Here's the story of one man against the rules and regulations: Fritz was between degrees back in 1974, and wanted to attend a basketball game at Raleigh's Reynolds Coliseum. "When I arrived with ticket in hand, the ticket-taker told me I wasn't allowed inside. It was a policy of the college not to let non-students in wheelchairs attend the games. I couldn't believe it! Finally, after a good deal of debate, they finally consented to give me a space to sit," he recalled.

From that hassle came a flurry of letter writing and lawyer-contacting and 504-citing.

Fritz first wrote a letter to Athletic Director Willis Casey, asking him to clarify the University's policy. Casey told him that the University had decided that people in wheelchairs were "dangerous" to themselves and others because they could not be removed quickly from the arena in case of fire, and that if they were allowed to sit on the floor of the gymnasium during the games, players might crash into them. This was, Casey said, not only a hazard to the people in wheelchairs, but to the players themselves.

Letters flew back and forth. Chancellor John Caldwell wrote Fritz that the University's policy of "no non-students in wheelchairs" could not, in any reasonable fashion, be interpreted as arbitrary discrimination. Caldwell further told Fritz that if he were able to move himself into a purchased seat, he would be admitted to the Coliseum. If he had to remain in his wheelchair, the University had no practical solution to meet his needs.

Caldwell concluded: "I'm sorry we have had this misunderstanding, Mr. Fritz. Naturally, we regret very much that your situation cannot be accommodated along with that of hundreds of others who miss the games."

Casey then commiserated with Fritz, writing that "we know this is all a disappointment to you." This letter was, to all intents and purposes, intended to be the end of the ballgame.

But Fritz, knowing the law, contacted Raleigh attorney Howard Twiggs, a member of the State legislature, and an advocate for the handicapped. Appalled at Fritz's experience, Twiggs, after conferring with Vocational Rehabilitation officials and the head of the Human Resources Department, wrote a stern letter to Caldwell.

"It is my current intention," wrote Twiggs, "to follow this matter through to conclusion to insure that Mr. Fritz and other handicapped citizens in this State have equal opportunity to attend athletic events. It is also my impression," continued Twiggs, "that such litigation could, and perhaps would, seriously endanger programs federally-funded at the University."

Twiggs cited the 1973 Rehabilitation Act, Section 504: "No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to, discrimination under any program or activity receiving federal financial assistance."

In short, Twiggs was fully prepared to take the University to court in behalf of his client. He then got a ruling from Attorney General Robert Morgan.

Morgan, now a United States Senator, and an advocate for handicapped people, cited this from a State law: "Handicapped persons have the same right as the able-bodied to full and free use of the streets, highways, sidewalks, walkways, public buildings, public facilities and all other buildings and facilities, both publicly and privately owned, which serve the public." Morgan was also urging the State to get on the ball and make all State-owned buildings barrier-free, and that included Reynolds Coliseum.

The upshot of this was a suddenly enlightened Chancellor and Athletic Director. Now, Fritz and other people in wheelchairs attending games at Reynolds sit in an area behind each basket. Their able-bodied friends may sit with them. All tickets sold at Reynolds Coliseum are printed with this request: "If you are handicapped, please let us know in advance of the game so that we may be sure you are accommodated."

Fritz, who is now project supervisor

for the University's Center for Urban Affairs, enjoys his rights as a sports spectator. He is a modest man, though. "I am not a militant," he admitted. "But I was really naive. If I had it to do all over again, I would have created a lot of public awareness of the incident."

As it was, not a line of the whole series of maneuvers reached a single member of the news media—until now.

Sexton and Fritz are naturally pleased with the Reynolds Coliseum results. Other State-owned stadiums and courts are fully accessible now. One of the most advanced approaches to the whole situation can be found in a small Presbyterian college, St. Andrews, in the Sandhills of North Carolina.

There, Dr. Rodger Decker, who runs the college's rehabilitation center, where severely handicapped students receive counseling, housing and therapy, was a guiding light behind the Edwin Pate Athletic Field, where teams from all over the county may compete. It was built at a cost of $400,000. Dr. Decker, a member of the local school board, offered plans to make the field events fully accessible.

"Everybody, of course, wants to be in the center, on the 50 yard line," he said. "But I don't believe in playing favorites, and I don't think handicapped people would want special privileges. But they do not want to be segregated."

The plan of the field's seating is so simple, Dr. Decker doesn't know why all stadiums cannot be remodeled for modest sums. The Pate Stadium has a ramp that curves from the ticket booth on up to the first row of seats. There, an eight-by-twenty-four-foot "apron" was added to the space in front of the row. This apron allows space for people using wheelchairs, as well as for their able-bodied friends, who can sit either on the concrete seat or bring their own folding chairs, and it allows other spectators to move freely to their own seats.

"I'm opposed to reserved seating for handicapped people," Dr. Decker said. "So we designed this multi-purpose area."

St Andrews' basketball court is accessible by virtue of its extra double doors that make it easy for people in wheelchairs to exit in case of fire.

Decker shrugged off the allegation that people in wheelchairs posed a hazard to anyone. "How do you determine whether or not somebody can get out of there quickly? Do you insist on giving a medical exam to everybody? Do you say, 'all sports fans 70 years old are too slow to get out fast enough?' Where do you draw the line?'

At the same time, he said he would reject the concept that people in wheelchairs may sit anywhere. "For their own good, they should be near fire exits. The super-militant position, I suppose, is okay, but the safety of the total group is the responsibility of everybody in that group."

Meanwhile, they're still "roaching it" in many ancient non-accessible sports arenas. Handicapped people in these areas may want to try "Fritz-ing it." A few letters turned a University around, and all it took was a reminder of a single law.

—Bette Elliott

Ms. Elliott is a free-lance writer.

Harvest House: A Simple Place

It is important to remember, when we speak of disabled people, that there is a large population of older people who have the same needs.

Many of the people in this group are not disabled in the standard sense of the word; but, because of the aging process, they require similar consideration in programs and planning.

This is a story about a group of older citizens, some disabled, some not, whose needs are not unlike our own.

The concept–if not the practice–of halfway houses for people with or mental problems, of centers for independent living for people with physical disabilities, of transitional housing, is well established. If the United States is to successfully "deinstitutionalize" people with varying disabilities, community living alternatives are essential.

Many people, however, have avoided institutions and have lived independently through long and productive lives. Many people, because of loss of family, age and disability, are finding independence on limited incomes to be an isolated, crime-ridden, and fearful existence in big cities, small towns and rural communities.

Harvest House in Washington, DC, is one alternative to isolation, loneliness and fear. It is a happy, simple place full of elderly and disabled elderly people living and learning together.

Harvest House is located near downtown Washington in a political district known as Ward Five. Ward Five has some 11,000 senior citizens, many living alone in rooms or in houses, cut off from social and neighborhood activity. Harvest House was founded to draw people back into contact with each other, while providing needed support services.

The House itself was an unused building on the grounds of a Carmelite monastery. It was in bad shape, but it was worth saving and using. So Others Might Eat (SOME), an ecumenical group which provides support to Washington's street people, is the parent of Harvest House.

Started in January 1979, Harvest House now has 10 residents and 45 registered participants in a day program. Harvest House provides meals, help with Social Security problems, advice on problems in dealing with various agencies, education, support, comfort and encouragement.

Harvest House is funded by a variety of means. It receives money from United Way, the Office of Aging, and other sources, including the District of Columbia government. The House is partially accessible, and planning is underway to make it fully accessible as soon as funds are raised.

Father John Adams, the creator and principle mover of Harvest House, talks of its difference: "It's a simple place. We rely heavily on volunteers because of our tight budget. We do have a paid live-in staff of five who, along with the residents, really keep the House running. Unfortunately, we haven't been able to attract VISTA (Volunteers in Service to America) volunteers, as we could certainly use them."

Residents pay $230 a month for room and board. This includes all meals and a snug little room. Meals and activities are taken together family style. Television watching, games, chatting, all are done together. This emphasis on togetherness stems from the complete isolation in which many of the people had lived prior to coming to Harvest House.

Harvest House, which was a vandalized wreck, was whipped into shape largely through the efforts of the small staff and volunteers. It meets city codes and is a pleasant, colorful and homey environment complete with plants, goldfish, birds, and the House dog, a rambuctious mixed breed who bounds about and is loved and cherished by the residents, some of whom take him for daily long walks.

People using wheelchairs roll by in the activities room, taking part in the exercise, craft and study programs. Some

of the most popular daytime activities are courses in literature and reading improvement.

Several people are employed outside the House, and others are employed by the House itself. Elaine, who is in her 60's and who uses a wheelchair, works at the House as an aide. Alberta, who is 80, Catherine who is 83, and Ursula who is 79, all hold jobs in the community.

Everyone who lives in the House takes responsibilities, and tasks are shared. Despite the racial and religious differences of the residents and participants in the day program, people realize that they have more in common than they have in differences. Everyone in Harvest House, for example, has been a victim of crime.

Harvest House is an alternative. An alternative to living alone and in fear. It is an opportunity to find a new lease on life, to make new friends, to develop new interests. It is not a "hospice," or a "nursing home." It is an alternative, a warm and caring home. Some people are like Mary, who has lived at Harvest House for six months, and is looking forward to returning to her own apartment. Others will stay.

Harvest House offers a wide range of activities. Recently, Black Awareness Week was celebrated by a trip to Washington's African Museum. Doctors, lawyers, government officials and professors offer regular lectures at Harvest House on a variety of subjects. Other outings include theatre and movie parties, visits to the Smithsonian Institution and places of interest in the Washington area.

Father Adams stresses that the emphasis at Harvest House is on simplicity. Using volunteers, the House regularly scouts Ward Five to locate people who need what it has to offer. The House hopes to open a summer camp this coming summer, which would allow for a wider range of physical and social activities for elderly disabled people living in the midst of a big city.

"We seek people who are 'one-roomers' primarily. They need Harvest House the most," says Father Adams. "Our aims are simple: We hope to foster a greater degree of independence and a sense of community."

Harvest House is a modest alternative. An alternative to loneliness, isolation, poverty, and despair. A simple place of dignity for those who might not find it elsewhere.

—Robert H. Ruffner

Mr. Ruffner is the director of Communications for the President's Committee.

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his course, and suggested that I return for an evaluation. I did. His interest in me and the confidence he had in his program pleased me. He was honest: "John, I won't claim to cure your stuttering. I can help you understand it and get control of it."

I remember telling Lisa, my wife, on a cold December night in 1978, after I returned from the two-hour evaluation with Dr. Hillis and his assistant, "I feel confident about the program and good about my work at the ACCD. I really want to put an all-out effort into controlling my speech!"

My speech therapy started in January 1979. Using a speech flow analyzer, an electronic timing network that monitors the continuity of speech, I had 10 three-hour sessions over the next three months. The sessions were tiring. There were moments when I became angry at the intensity that was required, and the repetitiousness of the therapy. However, my determination kept me coming back.

The course is complex and yet simple. My speech pattern was broken down into many small steps. These steps were taught one at a time. For example, I was given a series of phrases consisting of words containing three, four, or five syllables to read. When I was able to read a sufficient number of them without pausing, I moved on to reading longer phrases.

Eventually, I began reading sentences, and then paragraphs. When I did block or stutter, I repeated the phrase, syllable or sentence. If I stuttered more than three times in a specific time interval, about two minutes, I started the exercise over from the beginning.

Another part of the course consisted of answering questions from either the assistant or Dr. Hillis. Sometimes I would speak for five minutes or longer.

These skills were taught one at a time. Each new skill, whether it involved breathing, voice quality, or articulation had to be learned precisely. Each one built on the one that preceded it in a tight sequence. At first, each skill was exaggerated, and then toned down.The idea behind this therapy was to keep my speech flowing.

Dr. Hillis used an analogy with me: "Pretend you are on a roller coaster at the top of a hill before you speak. Let your speech flow like the roller coaster going downhill." Another analogy he used was: "Think of yourself driving a Buick with hydromatic drive."

Dr. Hillis emphasized that his program is not totally new or unique. It is one of a number of approaches developed over the past dozen years, stressing improvement of minute motor speech skills and accompanied by exact measurement of progress.

He believes that clinicians, whatever their specialty, should be able, and willing, to specify treatment goals for their patients and clients. Progress toward achieving stated goals needs to be measured regularly, with mathematical precision, and shared with patients or clients. "The test of a good therapist in *any* profession," he said, "is that he or she has the skill—and cares enough—to provide this kind of measurement.

There is more to the therapy than I have described. The important fact is that, for me, it works.

Shortly after beginning with Dr. Hillis, I was asked to go to Dallas, Texas, to attend one of the sessions of an annual Council of Exceptional Children meeting. I was to speak before a group of teachers on my stuttering.

I was nervous, and didn't want to repeat an experience I had recently had when giving a speech before a group at HEW. That speech had been praised more for the content than for the delivery. Because of my stuttering, I had felt angry and ashamed.

Afterward, when I met with Dr. Hillis and one of his assistants, I told them about my experience and asked them how I could avoid the same circumstances in Dallas. He told me how.

The next morning, I went to the session in Dallas. Three people spoke before me. They were good. While they were speaking, I concentrated on what I was going to read. Finally, my time came to speak.

I was scared and nervous. My hands were sweating. I told myself to relax. I tried to imagine myself on a roller coaster at the top of a hill. I looked at the people. There were about one hundred. I took a deep breath and started slowly, but confidently. I started down from the top of the roller coaster!

The night before, I had divided my speech into phrases consisting of words adding up to about twenty syllables. As I started reading my speech, I prolonged the first vowel of each sentence. I read the speech in phrases. I knew where I would have difficulty and had prepared myself.

The 25-minute speech rolled along like the lazy Mississippi River. When I was through, I realized the speech had been a success, the first real communication success of my life. The fear of stuttering had vanished for a while.

For the rest of the day, I was on a high. I made a second presentation in the afternoon. It was even better than the first one. I felt as though I were a new man, relaxed and confident.

I felt different. I *was* different. I knew that I could do the same thing again and again. I was thankful for the techniques Dr. Hillis had taught me.

After Dallas, there was Houston, where I made a one-hour presentation. I stuttered. But it wasn't as bad as it had been six months ago. I wasn't as nervous. I found that real concentration aided me, along with plenty of rest, and no alcoholic beverages before speaking.

Houston has been followed by appearances in other cities. While I still stutter, the decline has been fantastic. The change has made it easier for me to speak before groups. It has made my job easier. It has strengthened me personally.

A year's visibility through the ACCD and the media have resulted in a new role for me. Frequently, people ask me to speak before their groups on building communications programs, working with the press, and on the current status of disabled people.

In the past year, I have testified before Congress, worked with the White House on preparing energy relief legislation, and with Senator Javits' and Representative Paul Simon's staff members on energy legislation, and appeared on several television and radio programs.

My speech fluency and self confidence have continued to grow. Both also help me to do my job better. Finally, I feel, I have begun to meet some of those goals I mapped out for myself over a decade ago. Finally, I've established a place for myself in the communications field. It's a good feeling.

—John M. Williams.

Mr. Williams is the communications coordinator for the ACCD.

Welcome to the Smithsonian

A converted Washingtonian, I've settled into the lazy lassitude of near-native status. Like so many others who have become residents of this beautiful city, I often forget to take advantage of the rich historical and cultural variety offered by the museums, art galleries, and other exhibitions that tourists who come to the Nation's Capital stand in line for hours to see.

"Too busy," I say. "Other things to do." Both are true, but. . . . But, also, I use a wheelchair. After a busy day at work, feeding the cat, and reading the day's "Cathy" cartoon, I often decide not to venture out. Especially if I don't know the territory, or the accessibility features I'll find. A street without a curb-cut, or a too-narrow doorway can make an adventure a dubious prospect.

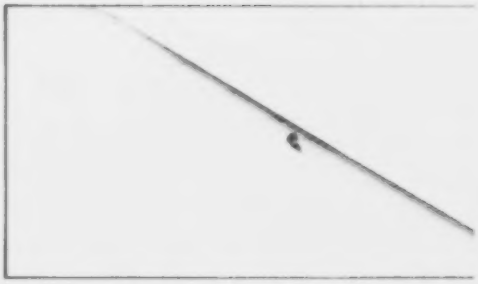
So, it was with a sense of personal foresight that I grabbed an early copy of the new brochure, "Smithsonian: A Guide for Disabled People." I told myself, "This will come in handy . . . when I get around to absorbing some culture!" So much for trite words to myself.

As I glanced through the attractive blue brochure, I found myself becoming more and more excited. I didn't even know that the "Smithsonian" is really comprised of 12 museums and the National Zoo . . . that deaf people can request interpreters for guided tours . . . that there are a variety of special features designed to enhance the attractions for blind persons.

And for people in wheelchairs, like me, ahhh . . . restaurants, restrooms, water fountains, telephones, parking, everything is now either completely accessible, or accessible with the readily-available assistance of the museum staff members.

When my boss asked me if I'd like to do a picture story on the new features, I jumped at the chance. Calling a good friend, Marilynne Tilson, who also uses a wheelchair, I arranged for her to meet me the next day at 1:30 p.m.

We'd look around for a while at the

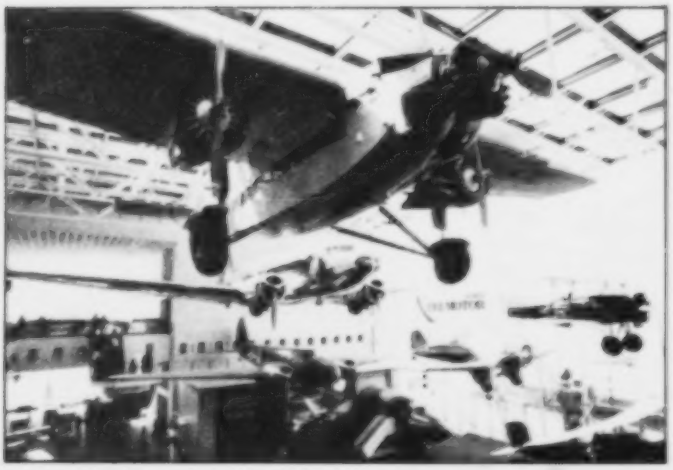


National Air and Space Museum, then pop across the street for a quick stop at the Hirshhorn. I figured we'd spend about two hours looking around, then I'd do some shopping downtown and still get home early.

How wrong I was! Blue guides in hand, we lingered at the Air and Space Museum. Like two schoolchildren there for the first time, we ohhed and ahhed. We posed and showed off like tourists in front of the national monuments. "Come see this . . . did you try that one? Over here!"

Hours later, we tore ourselves away from airplanes and gliders, and the lure of the skies, and headed for the Hirshhorn, that circular temple of art and visual edification. At the Hirshhorn, we were a little more sedate in our comments and highjinks, as befitted the setting.

Finally, Marilynne and I were happy, exhausted, and both possessed of massive cases of visual overload. We had seen, not too much (never!) but a



pleasant surfeit. As we headed back to our cars, I noticed, with a start of surprise, that it was almost five o'clock. So much for shopping! Pleasantly tired, I headed home, vowing to return again.

In fact, I'll give you odds that I'll make it to three or four museums, or maybe even five or six, this year. I can't wait to see the Insect Zoo at the Museum of Natural History, and the First Ladies' Gowns at the History and Technology Museum!

One thing is certain: It will be a lot easier for me, and other disabled people, now that we have the new booklet to guide us. What about you? Are you busy next Sunday? Maybe I'll see you there!

To obtain a copy of the free booklet, "Smithsonian: A Guide for Disabled People," write: The President's Committee on Employment of the Handicapped, Washington, DC 20210

—Lynn Park

Ms. Park is on the Communications staff of the President's Committee.

RSVP

Full-Color Issue . . .

I receive "Disabled USA" regularly and wish to congratulate the editorial staff for their excellent publication. The recent issue (Vol. 2, No. 10, 1979) was especially appealing with the increased use of color photography and sketches.

Frank S. Deyoe
Framingham, MA

Editorial Changes . . .

I have just received "Disabled USA," Vol. 3, No. 1, in which my story "And The Children Shall Lead Us" appears. The illustration is absolutely marvelous and surprisingly enough looks just like me. The editing was also quite good, though I would have appreciated some consulting, since in one or two places I disagree with the change. But on the whole I am extraordinarily pleased. I hope you are.

Irving Kenneth Zola, Ph.D.
Professor and Chair
Brandeis University
Waltham, MA

Ed. Note: *Unfortunately, time does not allow us to consult authors about editorial changes.*

Sampson and Delilah . . .

I have just finished reading your article on Judy ("Judy Heumann, Woman in Motion," Vol. 3, No. 2) and, after calling her, I just had to drop you a note.

Needless to say, the article really describes Judy to a "T," but you didn't go far enough. You didn't show how rough she could be with her friends in the clinches.

Bob Sampson
Vice President, United Airlines
Chicago, IL

Ed. Note: *The President's Committee has a new pairing which rivals Sampson and Delilah—Sampson and Heumann are the new Vice Chairpersons appointed by President Carter. Shear pleasure!*

The Sexuality Issue . . .

The last issue (Vol. 3, No. 2) of "Disabled USA" is absolutely outstanding. Congratulations.

Gunnar Dybwad
Professor Emeritus of Human Development
Brandeis University
Waltham, MA

We have just received our copy of the publication "Disabled USA," Vol. 3, No. 2, 1979. We feel that this issue is a particularly valuable one and could be used by our staff in other ways.

Marylyn Bruce
Dept. of Public Instruction
Des Moines, IA

I read the spendid issue of "Disabled USA" on sexuality of disabled people with great interest. I should like to use this issue as a resource in my classes in rehabilitation.

Joseph Newman, Professor
School of Education
University of Pittsburgh
Pittsburgh, PA

I want to express to you my appreciation for the publication. It is a very fine magazine, and gives me material I cannot get from other periodicals. I am a retired medical social worker, and work with the aged and handicapped (a word I like better than disabled, if I may add. I feel if they are handicapped they do not necessarily have to be disabled, but only handicapped to a degree . . .)

At any rate, what I have been doing is reading for a blind professor who is now working on her doctorate. She teaches at the university in our city. She had been preparing a thesis on sexuality for the blind, and then your Vol. 3, No. 2, 1979, came with an article dealing with the blind: "Look But Don't Touch: The Problems Blind Children Have Learning About Sexuality." I called her and read the whole article to her over the telephone. She was so glad to have me call this article to her attention.

Leah Epstein
Toledo, OH

As a psychologist who works with disabled individuals during acute rehabilitation, I was extremely impressed with your recent issue which addressed issues of sexuality.

I would like very much to make this issue available to our patients who are struggling with issues related to sexuality.

Stanley Ducharme, Ph.D., Chief
Psychology Services
Department of Rehabilitation Medicine
University Hospital
Boston, MA

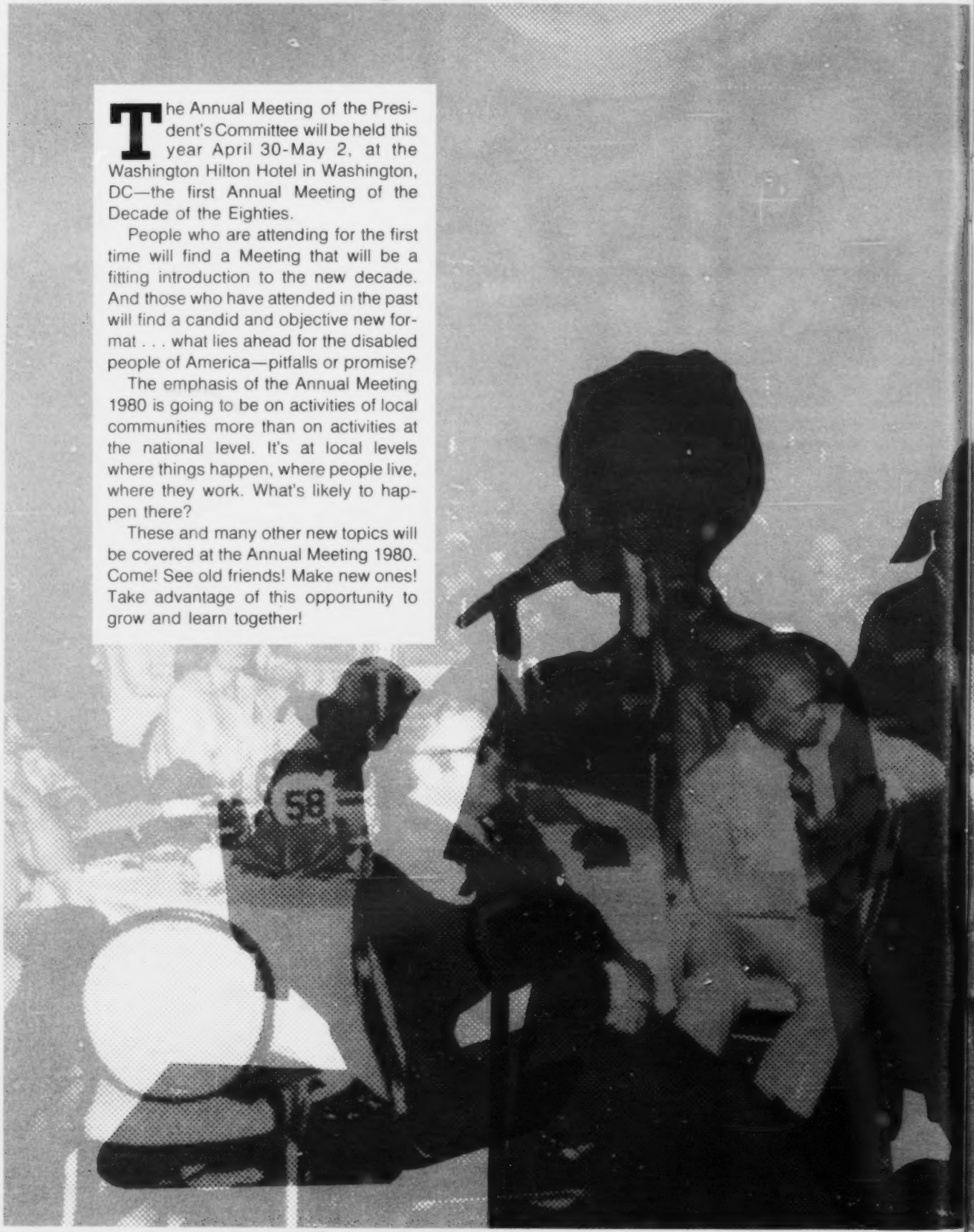
Since You Asked . . .

Am I correct in assuming that "Disabled USA" is basically a house organ which prints only material favorable to its point of view, rather than presenting various views on such topics as accessibility, etc.?

Walter F. Stromer
Mt. Vernon, IA

Ed. Note: *No.*

Annual Meeting 1980



The Annual Meeting of the President's Committee will be held this year April 30-May 2, at the Washington Hilton Hotel in Washington, DC—the first Annual Meeting of the Decade of the Eighties.

People who are attending for the first time will find a Meeting that will be a fitting introduction to the new decade. And those who have attended in the past will find a candid and objective new format . . . what lies ahead for the disabled people of America—pitfalls or promise?

The emphasis of the Annual Meeting 1980 is going to be on activities of local communities more than on activities at the national level. It's at local levels where things happen, where people live, where they work. What's likely to happen there?

These and many other new topics will be covered at the Annual Meeting 1980. Come! See old friends! Make new ones! Take advantage of this opportunity to grow and learn together!

the Chairman's Column

UPCOMING CONFERENCE . . . The Association on Handicapped Student Service Programs in Post-Secondary Education (AHSSPPE) will hold its Third National Conference, "The Handicapped Student on College Campuses—Advocacy, Responsibility, and Education," May 18-21, 1980, in Denver, Colorado, at the Plaza Cosmopolitan Hotel.

The conference program will include a wide range of topics relevant to accommodation of, and services to, handicapped students in post-secondary institutions. There will be opportunities for sharing information, discussion, and exploring mutual concerns.

Post secondary personnel, administrators, faculty, students, and representatives from organizations by/for the handicapped are encouraged to attend. For further information, write: Ron Blosser, Publicity Chair, AHSSPPE Conference, c/o Specialized Student Services, SIU-Carbondale, IL 62901. (618) 453-5738 (Voice or TTY).

WORTHY EMPLOYERS? . . . Each year the President's Committee co-sponsors two awards programs—one with the National Association for Retarded Citizens, and one with the Mental Health Association—to recognize employers who have been outstanding in their efforts to recruit and hire mentally handicapped people.

Both large and small employers qualify. In past years, winners have ranged from a large corporation in Boston, to a government agency in California, to a family-run pizzeria in a small Pennsylvania town.

Nomination forms are available from the President's Committee. If you know of a deserving employer of either mentally retarded or mentally restored workers, please write us for a nomination form: PCEH, Washington, DC 20210. It'll take only a few minutes to fill out. And who knows? Your nominee may be a winner!

ART CONFERENCE . . . A two-day international conference on "Creativity: The Arts and People with Disabilities," will take place at Courage Center in Minneapolis, Minnesota, June 20-21, 1980.

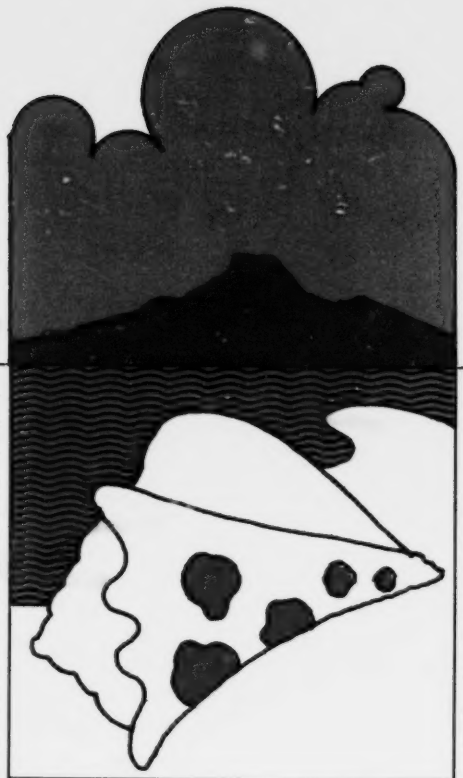
The conference is designed primarily for educators and professionals in the fields of rehabilitation, government, and the arts.

Fifteen individuals and groups from the U.S. and Canada will give presentations and demonstrations representing a variety of experiences involving the arts, including music, drama, dance, studio arts, and design, as they pertain to people with physical and mental disabilities, as well as people with hearing and vision disorders.

Registration fee is $50.00. Prearranged food and lodging are available on request. For more information and registration materials, contact: The Courage Center, 3815 Golden Valley Road, Golden Valley, Minnesota 55422. (612) 588-0811.

AGB CONVENTION . . . The 1980 International Convention of the Alexander Graham Bell Association for the Deaf will be held in Houston, Texas, June 24-28, 1980. The convention format will emphasize audience participation and information exchange, and will offer mini-seminars, poster sessions, crackerbarrel sessions, audiovisual programs, and 12 short courses.

Program topics include visual testing, syndromes, genetic counseling, reading, auditory training, parent's rights, multiply-handicapped, bilingual education, and a special emphasis on adolesence. For more information contact: Conference Department, Alexander Graham Bell Association for the Deaf, 3417 Volta Place, N.W., Washington, DC 20007. (202) 337-5220 (Voice and TTY).



PROJECT ACE . . . Two new publications for teachers interested in infusing career education into physical education and sport, grades K-12, have been developed by the American Alliance for Health, Physical Education, Recreation, and Dance (AAHPERD) through its career education project, Project ACE.

Weaving Career Education Into Physical Education and Sport: A Handbook presents practical activity ideas for career education infusion in the existing physical education curriculum. These activities were contributed by educators nationwide. The handbook is 300 pages, and the first 1,000 copies will be sold for $6.00 per copy.

The second publication, *Infusing Career Education Into Physical Education and Sport: Selected Writings,* is a collection of articles written by educators regarding the philosophy and rationale for career education infusion into existing curricula, specifically physical education and sport. This publication is 64 pages long, and the first 1,000 copies will be sold for $2.50.

For further information, contact: AAHPERD Publications, 1201 16th Street, N.W., Washington, DC 20036. (202) 833-5541.

ALOHA! . . . Now available for the mobility handicapped person are individual accessibility guidebooks to the islands of Oahu, Kauai, Maui and Hawaii in the State of Hawaii. Described are the accessibility features of hotels, restaurants, tourist attractions, libraries, post offices, government buildings, colleges and universities, parks, health facilities, shopping centers, auditoriums, and theatres. Guidebooks cost $1.00 each for postage and handling. To order, contact: Commission on the Handicapped, 250 S. King Street, Room 602, Honolulu, Hawaii 96813. Be sure to specify which island you're interested in.

HEED . . . As a result of a successful pilot program carried out in 1978, Management Woman, Inc. has established a new division, HEED, Inc. (Handicaped Employment and Economic Development, Inc.). HEED operates as a separate retainer search division and specializes in the recruitment of disabled men and women into corporations. To this end, HEED has been actively contacting affirmative action managers and directors of personnel to explore new areas of potential employment for professionals with disabilities.

HEED works with men and women who are visually impaired, hearing impaired, or who have mobility limitations. HEED recruits the professional who has attained at least a college degree. It operates as a clearinghouse, monitoring all new technological advances as they relate to the employment of the disabled. HEED recruits on a nationwide basis. All fees are charged directly to the corporation with no cost to the potential candidate. All resumes are kept confidential until HEED receives a search assignment in a particular field of expertise. At that time, they contact the candidate to arrange for an in-depth discussion about the new career opportunity.

Anyone interested in HEED's service is urged to send an updated resume and cover letter outlining career objectives, salary range and ability to relocate, to: Gerand Guarniero, Associate, HEED, A Division of Management Women, Inc., 115 East 57th Street, New York, NY (212) 888-8109.

NOW IN BRAILLE . . . The Port Authority of New York and New Jersey has now published a braille version of its comprehensive guide, *Services and Facilities for the Handicapped at Kennedy International, La Guardia and Newark International Airports.* The publication covers information about the facilities and services available to handicapped travelers at these airports. For free copies, write: Port Authority of New York and New Jersey, Aviation Public Services Division, One World Trade Center, Room 65 North, New York, NY 10048.

Harold Russell

VOL. 3 NO. 7, 1980

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BLEDUSA

abled People in China . . . Business,
, and Disabled People . . . and a story
about the Attitudes of Disabled
People Themselves . . .

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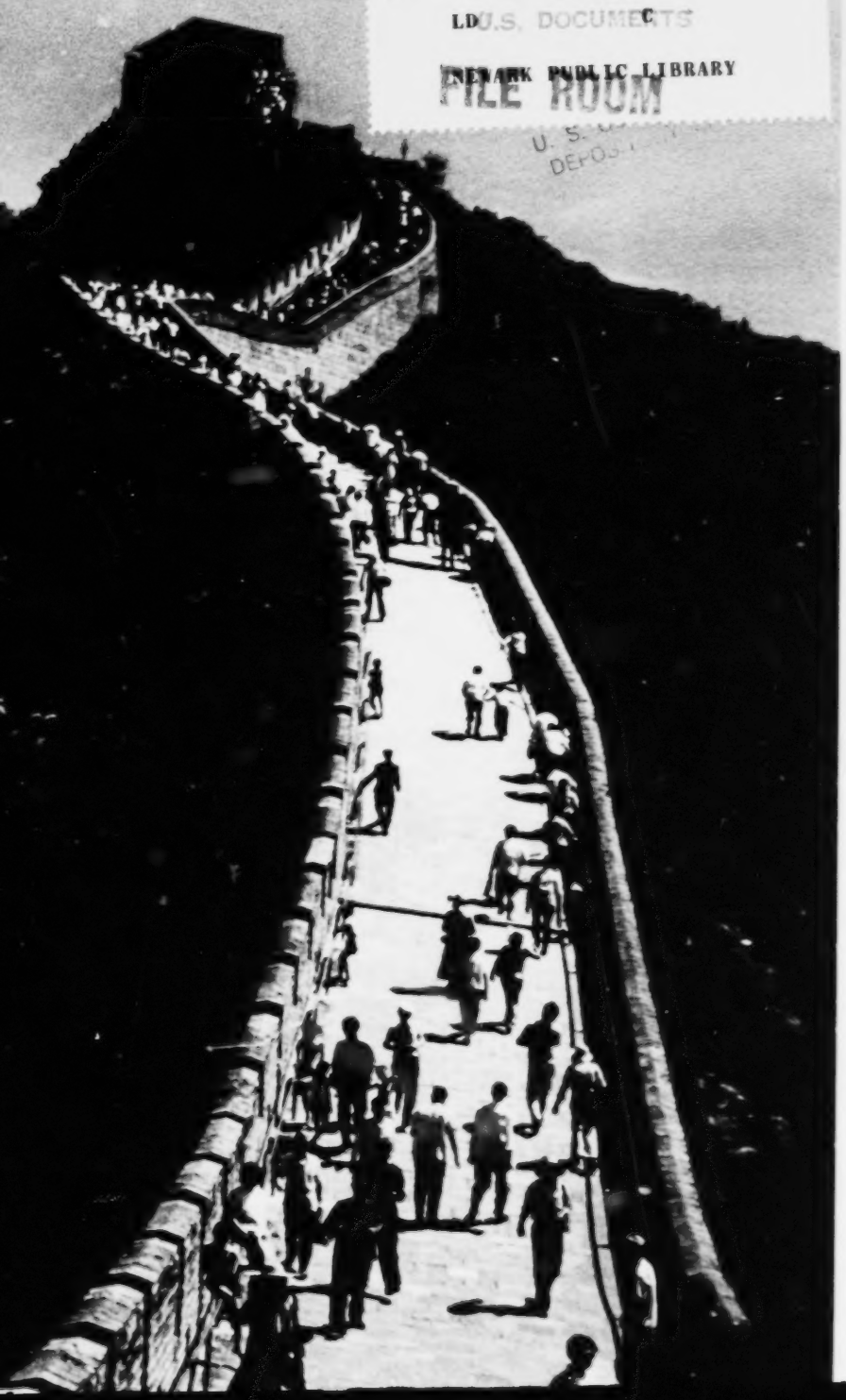

DISABLEDUSA

VOL. 3 NO. 7, 1980

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THE HANDICAPPED PEOPLE OF CHINA

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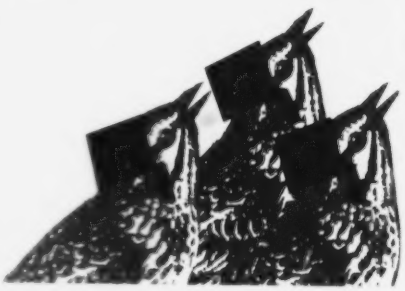

CAMPUS VOICES

The University of Michigan is adding the voices of disabled people to those that are heard on campus. Included: Exerpts from "The Advocate," the University's newsletter by disabled students.

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CHAIRMAN'S COLUMN

PHOTO CREDITS. Cover, Charles W. Harles Pages 2, 3, 4 and 5 (B/W), Charles W. Harles; pages 2, 3, 4 and 5 (color), John Davis; pages 15, 16, 17, 18, 19 and 20, Nation Park Service.

ART CREDITS: Page 8, Pat Morrison.

Harold Russell, Chairman

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Robert Lovelace, Art Director

DISABLED USA reports progress in opportunities for all handicapped workers, keeps Governors' and Community Committees informed of new ideas and activities, and provides all readers with general information concerning developments in rehabilitation and placement of people with disabilities. In a phrase, Disabled USA presents the case for disabled adults.

The Chairman of the President's Committee on Employment of the Handicapped has determined that the publication of this periodical is necessary in the transaction of the public business required by law of this Agency. Use of funds for printing this periodical has been approved by the Director of the Office of Management and Budget through August 15, 1981.

DISABLED USA encourages the submission of articles for publication by all readers, especially disabled people. Articles should be eight to ten, typewritten, doubled-spaced pages, written in an informal style. We also welcome letters from readers for the RSVP column. (All articles appearing in DISABLED USA may be reprinted with or without credit.)

THE PRESIDENT'S COMMITTEE ON EMPLOYMENT OF THE HANDICAPPED

The Handicapped People of China

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A winding alley in the outskirts of Peking, the People's Republic of China. People line both sides, so many that our tour bus barely can thread its way. They applaud. Nearly all the adults wear blue denim slacks and white shirts open at the the throat. The children wear gayer colors.

We approach the Peking wool and weaving factory, one of scores of factories throughout China that hire mainly physically handicapped people.

We swing into a courtyard; ahead of us the three-story factory with people leaning out of every window. Loud applause. And hands stretched out, thumbs up. A banner written in Chinese and English stating, "Warmly Welcome to China," flaps in the breeze.

The 12 of us get off the bus. We are part of a study group looking into China's activities for her handicapped people. A man in blue denim slacks and white shirt greets us, leads us up three flights of stairs, newly scrubbed with carbolic acid.

We enter a room and are greeted by a vigorous stocky middle-aged man—also denim slacks and white shirt—who is the political leader of the factory. The factory manager stands behind; he doesn't say much. Neither is handicapped.

We are motioned to sit down at two tables made from boards stretched across wooden desks. The political leader, Comrade Mung, nods to a young girl—also in blue slacks and white shirt—who pours green tea into hand-painted cups. We sip silently. As soon as our cups are empty the young girl refills them. Comrade Mung and three officials sit at a small table at one end of the room, whispering.

Twenty minutes pass. Comrade Mung clears his throat and welcomes us, an interpreter translating. Our group leader responds. Then, an opportunity to ask questions.

Q. *How many people here?*
A. Total, 467. Of them, 276 are handicapped—mainly deaf without speaking skills; some blind; very few with crippling conditions.
Q. *How do the handicapped workers compare with the rest?*
A. Every bit as productive. No difference.
Q. *Is it difficult for a handicapped person to get a job in Mainland China?*
A. (Blank stares, uncomprehending. Later we learned that everyone who wants to work can work; the Chinese government assigns jobs. There is no open labor market as in the USA.)

We Tour The Plant

The tour begins, up and down more freshly-scrubbed stairs. You have to be agile to work here.

A room on the third floor; a round of applause. All the workers here are deaf. They are weaving fronts and backs of sweaters by hand. Light blue, dark blue, off-white.

With her eyes, a smiling young lady invites me to sit at her work bench. She shows me what she is doing; she motions me to try. Other young women flock around to watch, tittering.

Down a flight of stairs where they are making sleeves for the sweaters. More applause. We shake hands with every worker, every one. We are in *their* world now, their guests. They show us hospitality in their own ways, we communicate with our eyes.

Then the first floor; huge looms making exquisite Chinese rugs, 9x12; for export. Each man and woman has a blueprint tacked to the wall, with details of color and pattern.

Weeks later, in the United States, I saw the rugs for sale in posh establishments in Los Angeles, New York and Washington. If only the purchasers could know they probably were admiring the handiwork of handicapped people!

How Tong Fu, Factory Chef

Since China encourages family togetherness, many of the handicapped workers bring their children to the factory. There is a day-care center and there are classrooms. Lunchtime, the youngsters eat with their parents, in a large dining hall.

So the factory has a chef, dancing-eyed, roly-poly, barrel-like How Tong Fu. He is deaf.

When the 12 of us file into his domain, the factory kitchen, he is in ecstacy. His body bobs back and forth, like one of those Chinese dolls with a round base that cannot be knocked over. He squeals with glee.

With a combination of pantomime and hand gesture, I ask him to demonstrate what he can do. He comprehends.

He bolts into the backyard, bounds back with three large yellow squashes. He scrubs them vigorously at the sink. He places them on the table, bounds out, returns with a wooden cutting board. He bounces over the wall, selects a huge gleaming cleaver, returns to the table.

He stands poised—a diver ready for the leap, a musician ready for the downbeat.

Suddenly, with such rapid motions that my eyes can't follow, he slices one squash into perfect cubes, all the same size. Just as suddenly, the second squash, perfect triangles, and the third, paper-thin slices we can almost see through.

He crosses his arms, cleaver in hand, body bobbing, awaiting our response. We applaud as loud as we can. He cannot hear, but we can see. He grins ear to ear, a high-pitched giggle coming from his throat. I shake his hands. He hugs me. His eyes dance. His body dances. The cleaver dances. Who needs words?

All Over China

Factories like this exist all over China. They are not sheltered workshops, not training establishments, but regular factories with production schedules and quality controls and problems of stepping up productivity.

In most factories handicapped workers receive the same wages as others. But we did visit one factory in Canton where wages and production quotas were lower.

The factories generally are under local Offices of Civil Affairs. These take their policy directions from an Office of Handicapped Affairs within the Ministry of Civil Affairs in Peking. Central control is loose; the real leadership comes from local jurisdictions.

There's a mix, handicapped and non handicapped, evenly balanced. All do the same work. A real effort goes on to assign people to tasks in accord with their abilities. As one factory manager put it: "We arrange for them according to each person's characteristics."

We see a variety of physical handicaps, but virtually no people with ambulatory problems. How would they climb the steps? If no steps, how would they get over the rough, rutted terrain from side road to factory?

One of our group asks a factory manager: "What about people with mental handicaps, mental retardation, mental illness?"

He looks astounded at the question: "Everybody knows these people can't work. They belong at home or in institutions."

We wonder silently how many retarded people are at work in a Chinese nation where 80 percent of the jobs are unskilled.

Signing

Because so many deaf people are employed in China's handicapped factories, signing becomes a way of life for

those who can hear. They sign as naturally as they speak. A blend of communication: Signing, talking.

At least one afternoon a week, usually Tuesday, every factory, plant, office, school, hospital and other establishment throughout Mainland China conducts political discussions. Topics are suggested from Peking. One of the Tuesdays we were there, the subject was the need to reassess China's heroes who had been deposed during the days of the Gang-of-Four.

At the handicapped factories, discussions are completely signed.

The Tung Shen Electronics Parts Company

This factory in Canton might represent a glimmer of China's future. Of its 400 workers, 100 are blind, 50 are deaf, more than 100 have other disabilities. They are not in dead-end jobs. All are encouraged to study technology; they get time off for it.

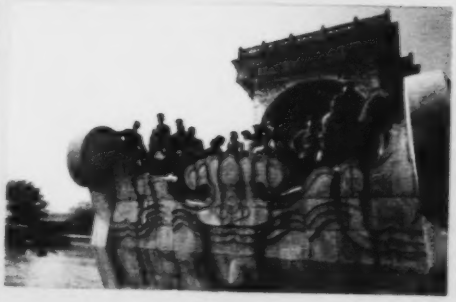
When the factory first opened, the handicapped employees did hand labor; now, 80 percent have learned to use machines. We tour the plant.

A deaf woman feeds a heavy piece of metal into a huge complex machine. When her working partner, who is blind, hears the clank of the metal, he exercises all his muscle to turn several large wheels and pull a lever, which processes the metal. When he is completely finished, he taps her (he knows where she is standing). She removes the processed metal.

A short, swarthy young man performs an intricate task on a machine in a corner. Our eyes meet. He beckons me. We shake hands warmly. He is deaf. By pantomime, he explains what he does. I understand. Then he points to his head, nods, laughs. It is as clear as if he had said the words: "You have to be smart to do what I do."

Handicapped People in Regular Industries

Obviously, not all handicapped people are employed in special factories. They work across the length and breadth of China—not all of them, by any means, but many. There are work disincentives in China, perhaps stronger than in the United States. Disability pen-



sions are high. Family units are strong, and tend to care for those who cannot work. Despite efforts to catch up with the rest of the world, most jobs in China are unskilled, calling for more brawn than brain.

Special efforts are made to find new jobs for workers injured in their plants or factories or communes. We raise this question with the manager of the Nanning Pongee Silk Textile Mill, near the Vietnam border.

"Let me show you," he says through the interpreter. He leaves the room, returns with a slight young man with black hair. His right arm is missing.

"He had a work accident," explains the manager. "So we taught him to paint posters and signs with his left hand." It turns out that all the posters throughout the plant, exhorting workers to produce more, are his handiwork.

The young man places a large sheet of white paper on a table. Holding it in place with his right stump, he begins to paint strong Chinese characters. We crowd about him. The manager watches him with the anxiety of a mother at her child's first piano recital. The sign emerges:

LONG LIVE FRIENDSHIP
BETWEEN CHINESE PEOPLE
AND AMERICAN PEOPLE

—NANNING PONGEE
KNITTING MILL

Commune

Half a day's drive from Nanning over mountain roads to the Double-Bridge People's Commune. Along the way people sit on their haunches, watching the bus.

We gather in the commune meeting hall. A print of Chairman Mao stares down from the wall. Again, green tea in china cups with hand-painted red berries. The commune's political leader welcomes us, through our interpreter. He tells us:

The commune's area is 300 square kilometers . . . It has 21 production brigades and, within them, 267 production units . . . 11,830 households, 59,500 people . . . Chief crops are rice and maize . . . Wages are 350 to 400 yuans per year (1.53 yuans per

American dollar) ... Complete health care is available at 50 cents a year ... There is one hospital, nine doctors, 21 medical workers, 93 "barefoot" doctors ... Also seven high schools, 21 middle schools, 75 primary schools ...

We interrupt to ask: What about handicapped people?

There are about 100, he says, mostly blind from birth. Oh, yes ... others, numbers not known, with work disabilities.

Do handicapped people work?

Mostly not. Work disability pensions are 80 percent of regular pay. Also, families need their handicapped members at home to baby-sit and keep house while husbands and wives go off to work in the fields.

And the blind people?

They are just beginning to learn to weave baskets in their homes. These will be distributed to commune members who need baskets.

Our silent reaction: "What! Basket weaving for blind people? But ... but they can do so much more!" But this is China. Even basket weaving is one step forward from vegetating. We said nothing.

Vocational Rehabilitation?

We could not find anything that even approximates the United States system. Medical rehabilitation, yes. Vocational, no.

Perhaps the reason is that China is such a vast country we could not see everything. Or perhaps the reason is that China is a labor-intensive country and does not yet feel the need for restoring the capacity to work for those who are handicapped. Or perhaps China is China, and is evolving in its own directions, unlike those of the Western World. Whatever, there's need for further examination.

East Is East

No comparisons, please. China is China. The United States is the United States.

In the rice paddies of Changsha, men and women up to their knees in water, plant rice, grain by grain. There is no such thing as completing their tasks; there always is more rice to plant, grain by grain.

In a village on the Li River in Southwest China, an old woman squats beside a pile of rocks. With a small mallet, she takes each rock, one by one, and taps it until it breaks into smaller rocks. One by one, tap-tap-tap, day after day.

In China, it is the doing that counts, not the getting done. It is the infinite patience, the eternal present and not the anticipated future.

What does this Chinese mode mean for her handicapped citizens? Forward movement, yes; but slow and steady, not fast.

Deeper than that, perhaps, a lasting acceptance of those who are handicapped. For China is an accepting society. She accepts processes; she accepts people.

—Bernard Posner

Mr. Posner is the executive director of the President's Committee.

Mental Health Worldwide

It started off as a well-meaning conference, like so many others. From 30 nations, we met in a seventh floor conference room in a Corbusier-designed glass and steel building on a Geneva hill, looking out at the Jura Mountains in one direction, and the city itself in the other.

The "advanced" countries got the floor first (although somebody wondered how "advanced" they really were), talking about such comfortably familiar concepts as deinstitutionalization, and unsupervised living for mentally ill people in New York's West Side, and halfway houses and transportation in suburbia.

We were there to give birth to a new worldwide organization to be called (after much word-quibbling) the World Association for the Rehabilitation of Psycho-Socially Disabled Persons.

A necessary organization? We had a gut feeling it was, because there is very little exchange of information across national borders.

The way the talk was going, some of us weren't so sure. If the advanced nations were to dominate matters, why not merely arrange for an exchange of journals and let it go at that?

Then, after we warmed up, we began to get a glimmer—just a glimmer—that there may be more to the world of rehabilitation of mentally ill people (or whatever you want to call them) than our own backyards and the backyards of others like us.

A researcher-psychiatrist in Colombia, South America, casually mentioned that 80 percent of the people in his country are untrained peasants. Do you think they know anything about deinstitutionalization?

A psychiatrist from Haiti asked me to remind him to tell me about voodoo in his country.

A social psychiatrist from Yugoslavia casually mentioned self-help groups of mentally ill people—not two or three, but hundreds.

The medical director of a mental hospital in Lebanon said that almost the entire country is rural. They can't get to institutions.

The conference livened up. If just part of the new organization's efforts could be turned over to this sort of exchange of ideas, what a refreshing world contribution!

Between sessions, I interviewed some of the delegates—nothing scientific about this, just random examples of home-grown problem solving. Highlights:

HAITI

Brand-new mental hospital there; many of the patients are in awe of the spotless corridors and trained psychiatrists and so many other members of the treatment team. All this can't possibly make them well, can it?

Many, after their release, visit their local voodoo doctor for what might be called a second opinion. With his reassurance, they feel well again—new men, new women.

But not without it.

JAPAN

Many books have come out in Japan on how to treat mental patients at home, without the need for hospitalization. These books were supposed to be written for parents. Not only did parents have a hard time understanding the books, but they didn't agree with them.

So parents took matters in their own hands and just wrote their own book. This one will be used widely.

YUGOSLAVIA

In Yugoslavia, self-help groups aren't merely tolerated; they are eagerly listened to by professionals. There are hundreds—for mentally ill people, people with alcohol problems, people with geriatric problems.

Who knows the problems better than the people who have them?

New trend in these many self-help groups: They are inviting professionals in, in limited numbers. Truly two-way communication.

COLOMBIA

Not a solution but an unusual problem.

For generations, mental illness was easily tolerated in the villages of Colombia. After all, these people with unusual behavior were not strangers. They were sons, daughters, mothers, fathers, aunts, uncles, neighbors.

It was easy to tolerate whatever they did, pretty easy to keep them at home.

But the cities have begun to lure the country people. They have been moving into slums at the edges of towns. Now, if they develop mental illness, there is nobody around to blink tolerantly and give the person some degree of friendly acceptance.

Now, it's to the hospital or some kind of institution—if there's room.

DENMARK

The scene: The town of Viborg this past summer. The main street of the city, plus a sports arena.

A fast-growing organization of mental patients and former mental patients (with a sprinkling of professionals) bearing the unusual name, "The Mad Movement," decided to stage a city-wide event. In Danish it's *GAH-LEH BEVAYTSEN*.

It was to be a huge parade, led by a band, also featuring floats—such as a psychiatrist in a hospital bed, being kept there against his will by patients. But the floats weren't bitter; they were in good humor.

The streets were jammed with townspeople. They waved and smiled at these people supposed to bear the stigma of "mental illness." They cheered and clapped.

And they crowded into the sports arena at the end of the march for a program staged by the patients, past and present.

Then it was over, although the reverberations of TV and press coverage lingered long after.

The psychiatrist who told me about it—the head of the Danish National Society for the Welfare of the Mentally Ill—puffed his pipe.

"Do you realize," he said, "these 300 people were not afraid to let the world know about their conditions, past or present?

"They could accept themselves—and their conditions. All of Viborg reacted the same matter-of-fact way.

"That's rehabilitation!"

—Bernard Posner

Mr. Posner is the executive director of the President's Committee.

Section 504: Training Consumers

"What was the first movie done about a coalition of disabled people?" asked Peter Myette.

His audience, a group of about 60 people, looked at each other, puzzled.

"It was the *Wizard of Oz*," he told them. "Dorothy has a directional handicap—she couldn't find her way home. The Lion had a mental illness, and was always afraid. The Scarecrow had a neurological disability—no brain!—and the Tin Man had a cardiac problem, he had no heart.

"Like most coalitions, each person had his own agenda. Dorothy wanted to go home, the Scarecrow wanted a brain, the Tin Man wanted a heart, and the Lion wanted courage. But they were united on one thing . . . finding the Wizard of Oz."

Myette, technical assistance coordinator for the American Coalition of Citizens with Disabilities (ACCD), is tall, and physically fit. He held the microphone like a gavel about to be pounded on the table. He continued the story until the point where the "coalition" returned to the Wizard of Oz with the witch's broomstick, which the Wizard had named as his price for granting the wishes of the delegation.

"Remember when Toto pulled back the curtain and the coalition found out that the Wizard of Oz was a person?" Myette prompted his audience. "What did Dorothy say? She said, 'You are a bad, bad man.' And he replied, 'No, I'm not a bad man. But I'm a bad wizard.' "

Myette explained, "And that's important. Because in your negotiations to enforce Section 504, you are going to run into a lot of bad administrators, and people who are bad within their particular role. But it's important to realize that they are not bad *people*."

The audience was intent and eager. A varied group, with many different characteristics and perspectives, many members of the group had a disability. Five were residents of Forest Haven, a local institution for retarded people.

The group met at the Washington Hotel, in Washington, DC. They came together for three and a half days of extensive training on the Section 504 provisions in the Rehabilitation Act of 1973.

Despite the fact that all participants were from the Metropolitan Washington area, they were provided with hotel rooms so that they would not need to go home evenings, thus providing more time for the workshop activities.

John Lancaster, director of the workshop, warned the participants that there was hard work ahead. "You'll get as much out of this as you put into it. So don't go South! Keep your heads up, pay attention, stay with us, and you'll learn a lot."

The first few sessions were devoted to an overview of Section 504, which states: "No otherwise qualified handicapped individual in the United States . . . shall, solely by reason of his handicap, be excluded from participation in, denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."

Participants learned about:

Recipients—those organizations and agencies which receive federal funds from the federal government, and are thus obliged to meet 504 provisions.

Self-evaluation plans—in which the recipients of federal funds evaluate where they have problems and need to become accessible.

Transition plans—in which recipients list how they plan to solve their accessibility problems.

Participants also received answers to questions they had. For example, one woman explained how she had participated in a parent-teacher conference. She and her wheelchair had had to be carried up the school steps.

Beverly Lucas, a lawyer from the Public Interest Law Center of Philadelphia, explained that the school was in violation of Section 504. "According to a policy interpretation of the Office of Civil Rights (OCR)," Lucas explained, "being carried in is not an acceptable way to provide access. The school should have a ramp."

After learning the abstract points, everyone divided into small groups. They received packets of materials which explained a situation the groups would learn to deal with.

"You are a member of a coalition of disabled people and their advocates in the city of Enfield. Your group has requested a meeting with the Superintendent of schools, and the Chairman of the school board, to discuss the board's plan for compliance with Section 504 and the HEW regulations. Your task is to secure a commitment to full compliance, and to obtain a statement about the board's priorities for compliance."

Other, more personal information was also provided: "The Chairman of the school board, James Wickersham, has been active in a number of civic organizations, and has served as fund raising chairman for the March of Dimes and the Heart Fund. For the past three years he has been a member of the State Chamber of Commerce Legislative Committee. A fact sheet on the Enfield Public Schools and a memorandum from one of your coalition members who attended the school board meeting is also attached."

Each group then went into a smaller room. They had one hour to plan their negotiation strategy before two project staff members, who pretended to be "officials," joined them. At first, people

were unsure how to proceed. But soon, someone took up the leadership role, and they formulated their strategy, just as a coalition would in real life.

Then the "officials" walked in, interrupting the discussion. In one group the two officials talked about how wonderful the Enfield School District was. They were not interrupted until the "coalition" leader recognized it as a delaying tactic. She interrupted to clarify the reason for the meeting.

"We're here to talk about Ms. Keller, a visually impaired teacher who has not been granted tenure. Your—"

"Well," explained the official, "we really feel it's exceptional that a blind woman can teach sc well, but when it comes to the question of granting tenure . . . that's a serious issue. She's done well so far, but—"

A member of the coalition interrupts. "But failure to grant a qualified handicapped person tenure is discrimination."

"What do you mean, discrimination," asked one of the "officials." "The fact that Ms. Keller was hired in the first place shows how undiscriminatory we are. We don't grant all teachers tenure. Tenure is a privilege to be earned!"

The discussion went on, while it seemed to be remaining constructive. Suddenly one of the "officials" said, "Okay folks, it's over! Let's discuss what happened."

The trainers, no longer "officials," then worked with the participants to analyze what went on. They gave feedback on negotiating techniques, and discussed appropriate follow-up. Throughout the procedure, they continuously made it clear that this was preparation for real-life meetings.

Marilyn McAdams, an intern from the House Select Education Subcommittee, felt she had benefitted from the workshop. "The negotiating was very helpful. I've negotiated before. Some things I solved by persistence, but I could have solved them much more quickly if I had had the skills I learned in the workshop. I think I'll be much more effective now."

Participants learned not only how to debate with officials, but also how to make complaints correctly. Some participants wondered why the OCR was providing grants to train people to complain effectively.

Rudy Frank, the project officer within OCR, who is responsible for monitoring funds spent on the training sessions, explained. "If the training workshops work, people will not need to bring up complaints. They will be able to educate the

recipients as to the law and the needs of disabled people in the community. Only when the process does not work, do people need to bring up a complaint. And apparently, that isn't the norm."

OCR provides grants for training sessions all over the country. The United States is divided into four regions, and organizations in these regions bid to do the training.

Barrier Free Environments is conducting workshops in the South. The Public Interest Law Center of Philadelphia and the American Coalition of Citizens with Disabilities are conducting workshops in the Northeastern region. And the Center for Independent Living is handling the West and Mideast.

According to Frank, about 2,400 disabled consumers are trained each year. There are also workshops in 504 requirements for directors of organizations that receive funds from HEW, and for other officials.

Workshops are evaluated by OCR in many ways. Participants in some cities are given tests to see what they have learned. But, according to Frank, "the more meaningful measure is what happens to the world as result of the training. We try to get the workshops to record their results and report back to us on a periodic basis about what the participants have done, and how their actions have affected recipients."

What has happened in the "real world" as a result of the workshops? Some examples:

In Arthur, Nebraska, a high school sophomore named Gene Garner successfully tackled accessibility problems in his school. Ramps were installed, and sidewalks were widened.

Harold Kuehle, of Cape Girardeau, Missouri, worked with a State university and a public school system to help them develop their self evaluation and transition plans. He also obtained funds from the Junior Chamber of Commerce for curb cuts in his city, and convinced local businessmen to put up signs indicating accessible parking.

Terry Wallace, from Thief River Falls, Minnesota, distributed information on Section 504 to chief administrators and school board members in the northwestern part of his State. He also delivered a workshop to these school personnel.

Wallace and his employer, the Northwestern Minnesota Educational Cooperative Service Unit, provided information and support to local schools. He has also worked with his local division of vocational rehabilitation.

In many States, citizens have testified at hearings and have worked within their consumer organizations, sharing what they learn with other handicapped peo-

ple and advocates. Some Section 504 complaints have resulted. However, in some States, the training workshops have produced no apparent results.

In the Washington, DC, workshop, it was hoped that consumers attending the workshop would work for implementation of 504 long after the workshop was completed.

After two and one half days of learning about Section 504, the participants again met as a large group.

Pete Myette explained, "Now the real work of this workshop begins. Up until now, you've been learning how to implement 504. Now we're going to start to do it.

"In order to negotiate your way out of this room, you're going to have to write down two targets in DC that are not in compliance with 504. There will be no dinner; there will be no reception. Someone is at the door blocking your way, if you don't write down two targets for 504 enforcement.

"You have 30 seconds," he stated. "It might be the most important 30 seconds in the next 30 years."

People pulled paper out of their packets and began to write. After 30 seconds, Myette asked everyone to read off one of their objectives. Several staff members wrote them in large letters on white paper in front of the room.

The next morning, participants received a typed list of objectives. Myette explained that they would be meeting in their role-playing groups. Only this time, they would be meeting for real.

"Each group will choose an objective that you will work towards after this conference. Don't necessarily choose the most important one. Choose the one that's most likely to succeed. Make sure your objective is realistic.

"Everybody will be assigned a task, just like you did in your negotiating session. Write down what the group decides. That way, you'll be sure to remember.

"We also need to know what kind of help you will need from us. We are making arrangements to provide technical assistance. What is technical assistance? It could include help with strategy, negotiations, or legal assistance. Maybe you need some information on funding or publicity. It could mean any type of help that you think you need."

Before telling the participants to divide into their small groups, Myette warned, "Remember, don't take on more than five percent of the world's problems in a year. Be sure to be realistic in your goals!"

The people went to their assigned groups. Each group was detailing the local objectives, targets, strategies, specific tasks, and the technical assistance needed from the ACCD staff members. In some groups, a chairperson was selected from among the members who took leadership. However, in other groups, the ACCD staff member assigned tasks to the participants.

One group decided to procure TTY and interpreter services for deaf people at all DC-area hospitals and health care facilities. Pam Anderson, Rafael Glower, and Tom Downes agreed to write a letter stating the accessibility problems of deaf people. The group would meet again to react to the hospitals' responses.

Another group chose to fight for equal access to legal research material for visually handicapped students at a DC-area university. They decided to determine the status of Section 504 implementation, and to see if there were groups of disabled students there. They would then request a negotiating meeting with the appropriate person.

What will happen in DC? Will the groups continue to work hard towards these objectives? According to Doris Ray, a participant, "Our group did set up a specific date and a specific place to meet."

On the other hand, four days after the workshop, Louis Thurston, another participant, stated that his co-chairman had resigned. "Most people, when they're at a workshop, are real into it, you know, Rah! Rah! Rah! But when they leave, they go back to the same old routine. And their interest in 504 dies down."

In order to keep the interest kindled, ACCD is requesting proposals from advocacy and self-help groups in the Northeastern States. They are offering $2,850 to State and local organizations willing to provide ongoing help to the workshop participants.

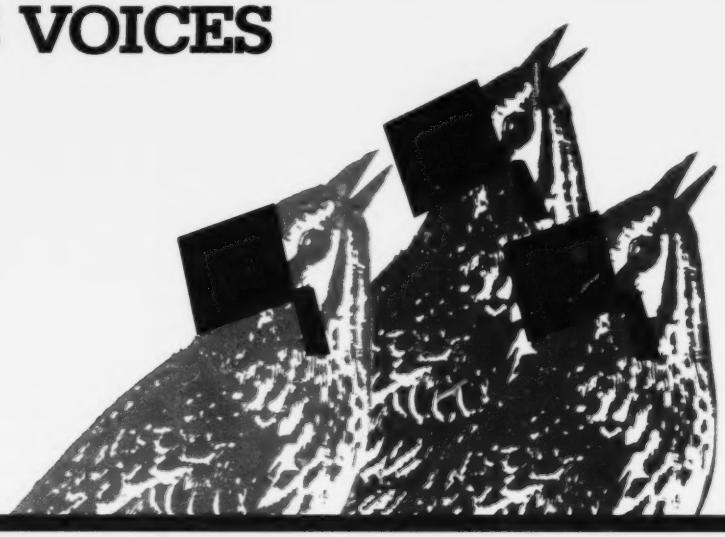
Martha Sneed, a woman with severe cerebral palsy who has spent her life at Forest Haven, explained, "I feel stronger about getting a home outside the institution now, because I know about the law."

Cecil Gobbles, also a resident of Forest Haven, explained, "I feel I can use what I learned here, by telling it all to the administration of Forest Haven. No clients have ever talked to the superintendent before. But now I know about Section 504—the specifics of the law. Now I feel stronger. I have met with other disabled people and feel powerful."

—Dale Brown

Ms. Brown is on the Communications staff of the President's Committee.

CAMPUS VOICES



A number of years ago, I was involved in the then-hot area of encouraging universities to establish foreign students advisory offices on their campuses. With the passage of time, we've seen foreign students on American campuses grow into a huge business. Indeed, some universities seem to thrive exclusively on foreign students.

While today the foreign student is a regular fixture on American campuses, there was considerable initial resistance to the idea of foreign students with their attendant cultural and linguistic problems.

Many universities saw the foreign student in those days as a potential drain on campus resources and, most importantly, on university funds. *Tempus Fugit*. Today, the foreign student is welcomed, indeed sought after, as a valuable addition to a university's life and budget.

Will the same phenomena happen to the disabled student? As more and more universities establish disabled student advisory offices, the same resistance can be found. Disabled students are going to be a drain; too expensive, not an addition to campus life and university budget.

Offices for disabled students are spending valuable and limited resources in fighting vocational rehabilitation programs, which are refusing to provide needed support services to disabled students, since these vocational rehabilitation offices are maintaining that these support services are the obligation of the university.

The university is maintaining that it will be financially ruined if it alone must provide readers for blind students, sign language interpreters for deaf students, ramps and accessible dormitories, classrooms and other facilities for students in wheelchairs, reading machines and tutors for learning disabled students, and support facilities for students with emotional or psychiatric disabilities.

A long list of needs and requirements. But, most universities have experienced much of this before. Yes, with foreign students and their special requirements for tutors, readers, and support services in finding housing, in helping bridge the cultural gaps, in establishing language laboratories, in a variety of ways.

The University of Michigan in Ann Arbor is a case in point. The University of Michigan has long offered foreign students a variety of specialized services to enable them to successfully attend this large and prestigious institution.

Today, it is offering disabled students a growing number of services which they, in their turn, need to successfully compete. The Disabled Student Services Office at the University is naturally running into resistance and financial problems and all those other things that go along with change.

It has found that in order to be effective, it cannot take a passive role at the University. It must offer the support services to the disabled student as needed, actively seek new disabled students, and be equally active in advocating the rights of disabled students throughout the University.

The Disabled Student Services Office is involved in battles with the vocational rehabilitation services over who is responsible for what. It is active in helping students with their financial problems through scholarships and the Social Security Administration; in placing students in part time jobs; and as graduation looms, in seeking full-time jobs compatible with their educational credentials. The Office also offers lectures, programs, and awareness events.

It also offers disabled students an opportunity to speak out through a monthly newsletter, "The Advocate." A selection of these students' recent articles from "The Advocate" serves as a sampling of what is going on in a major university today. I only regret that I don't have access to some of the pieces written by foreign students some 15 to 20 years ago to share at the same time. The comparison, I'm sure, would produce startling similarities.

It may be hard to be the new voice on campus, but it can produce results for disabled students, just as it did for foreign students. From rejection, to being wooed in less than a generation, from being "problems" and "too expensive" to becoming a vital and integral part of a sophisticated university community.

The address of the Disabled Students Services Office is the University of Michigan, 2211 Michigan Union, Ann Arbor, MI 48109. James Kubaiko is the director.

—Robert H. Ruffner

Mr. Ruffner is the director of Communications for the President's Committee.

Academic Apathy

After a tiring day of classes Luis Pena, a blind English Language Institute student, wondered whether or not he should attend an Assertiveness Training Meeting sponsored by Disabled Student Services (DSS).

The Union was a long way from his small room in Bates I; it looked like rain, and besides, assertiveness, he had been told, was not one of his weaknesses. But it might be useful. Since coming to America for the first time in 1975, from Columbia, Luis had learned to value his independence and the programs that prompted it, programs that did not exist in his native country.

He had been involved with DSS since coming to the University of Michigan, and wished to continue that involvement. He decided to attend the meeting. He was the only disabled student in the entire University who decided to attend that meeting.

The scheduled speaker, Jane Hassinger, was disappointed—perhaps insulted. Luis Pena was shocked and unbelieving. He thought of the disabled minority in his own impoverished country, where such concepts as assertiveness and equal rights were lost in the daily struggle for basic needs. Columbia had little to offer its blind citizens. Combined schools for the blind and deaf received minimal funding. Basic braille instruction was available, but psychological and social matters were largely ignored.

Luis was luckier than most Columbians in that he was able to come to America for training. He attended the Arkansas Rehabilitation Center for the Blind, and soon took on the independence characteristic of disabled Americans. With this positive attitude, he returned to Columbia to attend college.

There he found not only another country, but another state of mind. His handicapped countrymen were mired in hopelessness. They were dependent, psychologically and economically, on an indifferent public. For not only were services and programs lacking, but public prejudice fostered low self-esteem and bitterness.

After five semesters of psychology at the top of his class, Luis decided to return to the U.S. for further study. He chose the University of Michigan because of its extensive program for the handicapped. He cites assistance they have given him, ranging from obtaining readers and braille paper, to getting a visa.

His shock at finding an empty hall, a hall that could have been filled a hundred times over with disabled people from his homeland, is understandable. The reason why that hall was empty remains, however, a disconcerting mystery.

504 Personified

Tucked up on the third floor of the School of Education Building, the Department of Special Education lies. Fortunately for me, I discovered its existence. I say fortunately, for I had lost my way.

Deafness had undermined my feelings of self-worth and confidence. I literally withdrew from life. The essence of my being evolved around communication. Teaching was my profession, my life, for many years. To resign from life because I could no longer stand the strain of lip reading 30 youngsters everyday was devastating.

Getting back into the mainstream, finding myself by learning to live with a profound bilateral hearing loss has been no easy task, but a worthwhile and strengthening one.

I decided to become a teacher of the hearing impaired, and as I see that goal in sight, I feel it would be helpful for others to be aware of how this University assists its handicapped students. In particular, the experiences I have had trying to obtain my master's in Special Education may be enlightening.

I began as a non-degree seeking student, having been advised to try a few courses and see what I wanted to do. After completing my first course, I decided to pursue my master's degree. I felt driven to succeed in order to survive. Survival to me meant communication.

Frankly, I was tired of feeling alone—left out. I knew it was up to me to change that feeling.

Many times I was ready to give up. To gain admittance to Rackham required the full limits of my patience. I became used to the comments—

"Do you really think you can do this?"

"Don't take on too much."

"I'm not sure whether you can handle the work in that class."

After having worn a path from Academic Services, up to the Special Education department, across campus to graduate school, I began to feel that a great many people were uncomfortable about allowing a deaf student into U of M. I was advised that perhaps I should reconsider becoming an educator for the hearing impaired.

"Have you ever thought of becoming an audiologist?" I did finally convince them that I could handle my chosen program. And after making countless visits to Academic Services, I finally acquired a letter of acceptance into graduate school.

It has been a learning experience, for not only me but for many of my professors. I need an interpreter, a person who uses sign language to communicate the lecture to me. I also need a person to take notes for me as I am busy watching my interpreter. Comments such as, "most of my hearing-impaired students can lip read," caused me to feel inadequate. I have been told that I am an excellent lip reader, but even the best can read only approximately 50 percent. How do you lip read the back of a professor's head?

Most of my professors and fellow classmates have tried to be helpful. By the end of each semester I felt that more understanding and awareness of deafness was reached. Comments such as:

"Oh, but you can talk."

"You don't look deaf."

"Can you read?" (at the library!) began to fade, and I could see respect for me as a person take their place.

As I mentioned previously, I do require an interpreter, and this has been one of the most frustrating areas in my endeavor to reach my goal. The regulation cited in Section 504 of the Rehabilitation Act states as follows:

"(2) Auxiliary aids may include taped texts, interpreters or other effective methods of making orally delivered materials available to students with hearing impairments."

And Section 504 claims that "no handicapped student" should be "subjected to discrimination . . . because of the absence of educational auxiliary aids."

The University's position is that it is not their responsibility to supply interpreter services. They feel it is the responsibility of vocational rehabilitation services. On the other hand, vocational rehabilitation services feels that it is the University's responsibility.

Where do I fit into these two opposing teams? In the end I am the loser. This semester I was without an interpreter in an audiology class until October 12th. Luckily, I have one of the most aware and superb professors I have ever encountered. Thus, I managed, but it created an added strain on me as well as my professor.

The University of Michigan is fighting this law and I personally believe they are wrong. There will be more and more handicapped students demanding their rights to acquire a post-secondary education. I challenge the school to prove how enlightened it is, and to begin implementing Section 504 with commitment to assist the handicapped and to increase awareness among the total faculty. Mainstreaming isn't easy, but from firsthand experience, it can be rewarding to all concerned.

These two articles are reprinted from "The Advocate," the newsletter of the University of Michigan's Office of Disabled Student Services.

The National Park Service

Steve Stone, a recreation planner with the National Park Service, took a 97-mile "run" on the Colorado River between Lee's Ferry and Phantom Ranch in the Grand Canyon National Park. In the middle of August, he and three river managers ran some of the most notorious rapids in Colorado.

The trip was routine, but Steve Stone was not their typical passenger. He uses a wheelchair. Arrangements for him were not elaborate. Towage was placed to provide back support and a rope was hung to give him handholds. He was moved on and off the boat each day by rangers.

Stone was able to enjoy this experience because of the new movement towards accessibility by the National Park Service.

The National Park System contains most of the country's natural wonders and major historic memorials. The 321 diverse sites range from the great parks

of the Rocky Mountains and the Sierra Nevada, to brilliantly-colored desert canyons; from the barrier islands of the coasts to both active and extinct volcanoes; from scenic lakes to wild rivers.

Historical sites include ruins of the dwellings of Indian tribes; fossils preserved for millions of years; birthplaces, homes or worksites of celebrated Americans; frontier forts, and battlefields of the Revolutionary and Civil Wars. Would-be visitors who cannot visit the national parks because of lack of access are denied some of America's most profound experiences.

Like other organizations, the National Park Service had little knowledge of the needs of handicapped individuals years ago, when the parking lots, comfort stations and visitor centers were originally built.

Now, Director William J. Whalen says, "We are determined to rectify those oversights, and to make up for lost time!"

All features cannot be made fully accessible. Sometimes removing the obstructions would destroy the values for which the sites are reserved. Rugged or fragile terrain, the scope of the changes needed to build accessible facilities, and the age or characteristics of some historic buildings are some factors which make providing accessibility a very difficult task.

Still, the National Park Service has made great progress toward eliminating barriers, and much more is being done to make the parks accessible, and open to everyone.

Parks are being made accessible in two ways. The first is by removing architectural barriers. The second is by providing information that everyone can understand.

To better understand how to remove barriers, Don Squire, former superintendent of Walnut Canyon National Monument, put himself in a wheelchair one day to see how well he could get along in his own park. He found the restrooms hard to enter, and the drinking fountains and telephones almost impossible to reach. After that experience, he began a crusade for "special populations."

Squire had parking designed for handicapped people. Some drinking fountains and public telephones were lowered. Grab bars were installed in the bathrooms. An accessible walkway was built to a picnic area.

His second wheelchair tour was considerably easier!

"What we have found," says Director Whalen, "is that visitors do not want to be singled out, to have their differences or individual characteristics noted. What they do want is to be able to see, fully experience, and learn about the parks as far as possible without interference or unusual help. Our goal is to make it possible for everyone to do this.

"Especially in the national parks, providing access for everyone is part of that 'pursuit of happiness' that Americans believe is one of the rights of all persons."

The National Park Service does not limit its program to architectural barriers. Communications barriers are being systematically attacked as well. Through interpretative programs, the Service informs all visitors about a park's geology, biology and zoology, the effects of the seasons, and the historical events that took place at the sites. The interpretative programs help visitors understand the character and importance of the sites.

For this reason, the Park Service is broadening these informational activities. Trails are being constructed for those who have sensory impairments. Captioned films and slide programs are being developed.

Research is being conducted on trail signs combining both large letters and braille. TTYs are being installed to permit deaf persons access to telephone answering services, and staff members at many national parks are learning sign language.

Cassettes and tape players are also available at visitor center information desks for use of blind people.

With these changes, disabled visitors now have access to the interpretative programs, along with other visitors.

With all the changes which make it possible for a disabled person to, in Director Whalen's words, ". . . fully experience . . . the parks . . . without interference," there are still times when

Examples of Barrier Removal

Some examples of barrier removal at National Park sites include: ***Mammouth Cave National Park***, Kentucky. For the past two years, visitors using wheelchairs have been offered a daily tour. They can descend to the caves by elevator, and take a two-hour trip in dry passageways through the gypsum, crystalline formations, known for their fantastic shapes.

Everglades National Park of Florida features interpretative trails—either hard surface or boardwalk—on which any visitor can go out into the fascinating and varied environs of the park. They see the "sawgrass" glades and the mangroves (which the Indians call "the tree that walks"). They visit the sloughs where alligators, great wading birds, and other wildlife concentrate during the winter.

Currently, the accessible visitor center offers audio-visual and motion picture programs and exhibits. Modifications of other essential essential facilities are underway throughout the park.

The Lincoln Memorial in Washington, DC, with its 19-foot-high seated statue of the Great Emancipator, is one of the city's most visited shrines. An elevator has been installed as an alternative to the 59 steps leading to the principal chamber. There is designated parking for handicapped people, and accessible restrooms and drinking fountains.

The White House. People with disabilities can go directly to the northeast gate for prompt attention. Wheelchairs may be borrowed for the tour. From the gate, and throughout the lower floor and the grounds, all paths and floors are fully accessible. Groups can arrange special tours, and there are tours conducted by guides who know sign language.

The National Mall. More than 100 curb cuts have been made in the great open space bordered by the Capitol, the Potomac River, and Constitution and Independence Avenues. Four accessible bathrooms and drinking fountains are available.

Gettysburg National Military Park in Pennsylvania, recently installed a field induction "loop system" in the auditorium where Civil War battles are explained. This enables people with hearing aids to clearly understand what is said.

Fort McHenry National Monument in Maryland (whose successful defense inspired Francis Scott Key to write "The Star Spangled Banner") and Hopewell Village National Historic Site (an early iron-making community in Pennsylvania) provide self-guiding walking tours for the print-handicapped. For 16 other parks, edited cassette recordings of park folders have been produced.

assistance is necessary. Steve Stone found this out when he shot the rapids of the Colorado River.

But, Stone says the trip has widened his view of the meaning of "accessibility." In order to fully experience the trip, he needed special help. Stone elaborates: "For many, seeking to be independent, it has been psychologically unacceptable to be carried from place to place. But for such an exciting experience, it was a small price to pay."

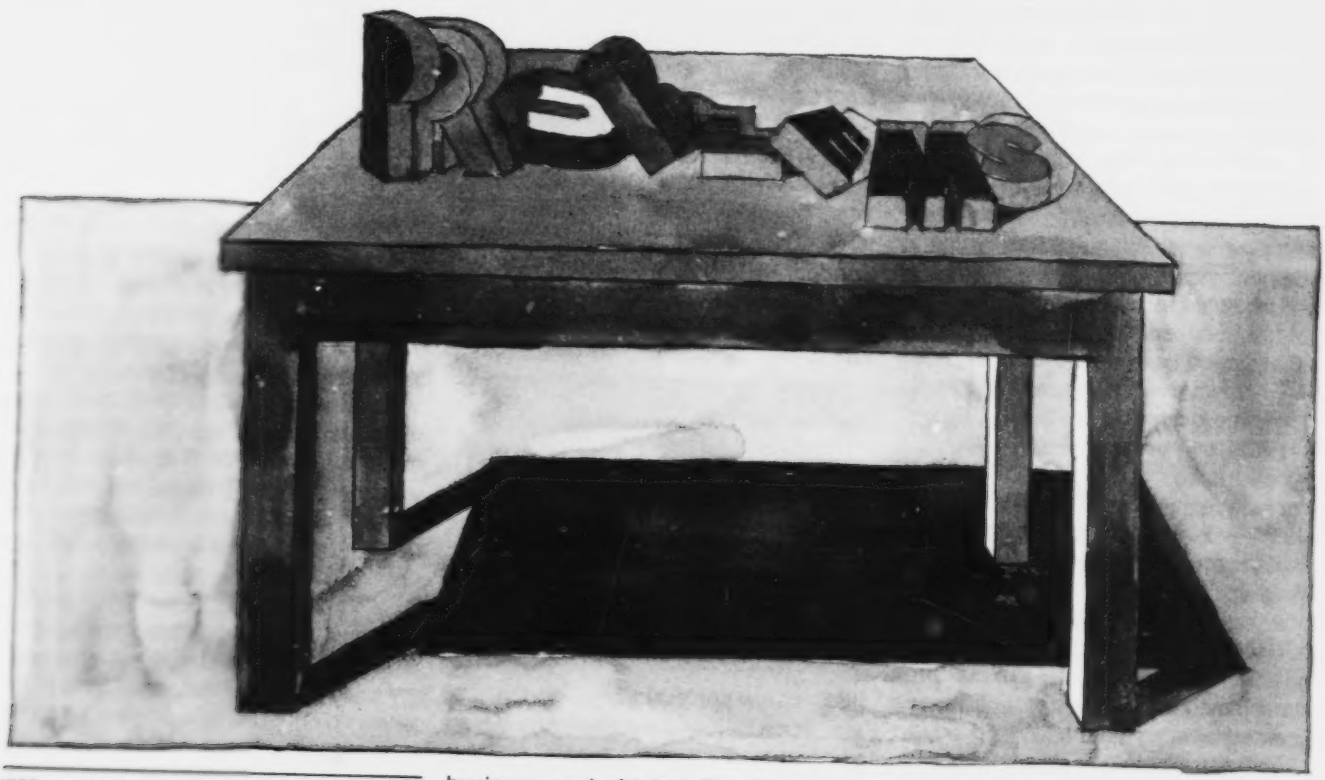
Now the Park Service is hiring other disabled people like Stone. They are teaching National Park System planners "total accessibility awareness." In this way, the Park Service is making as much of the National Park System as possible usable by everyone. And, when that is not possible, they are hoping other disabled people, like Steve Stone, will widen their views on the meaning of accessibility.

—Grant W. Midgley

Mr. Midgley is a public information specialist with the National Park Service.

Putting Problems on the Table

Representatives of Business, Labor and the Disabled
Discuss Affirmative Action



"Who shall hear of us in the time to come? Let him say there was a burst of fragrance from black branches."

—William Carlos Williams

It was a cold, damp day. The kind of day you'd rather spend in the cozy snugness of your own surroundings. But instead, we were all sitting in a conference room waiting for an uncertain meeting to begin.

The room had a chill in it, the way goverment offices all do now, since energy regulations keep the thermostats down. But, it was more than that. The chill was intensified by the people in the room. Despite polite conversation, there was no warmth generated among the group sitting around the table.

The group was made up of three factions: Representatives of the disabled, of business, and of labor. The President's Committee had invited the groups to a discussion of affirmative action.

Disabled people were to present their views; business and labor, their views. This was to be a chance to listen to differing points of view, a time to explain positions without having to give up territory.

Five questions, written and circulated in advance by the President's Committee, were the guidelines for discussion:

1. What is your view of requiring goals and timetables for Section 503, along the lines established for other affirmative action programs?

2. What is the impact of pre-employment physical examinations in the employment process, and how do they affect employment of the handicapped?

3. What are the ramifications of labor union bargaining agreements on employment of the handicapped?

4. What are the pros and cons of requiring that a person be able to do only the "essential functions" of a job, versus being able to do only "job-related functions"?

5. What do you see as the major problem in affirmative action for handicapped people in Title V?

One of the representatives of the disabled spoke first: "Why are we using these questions? Other questions should have been asked. Or they could have been more neutrally phrased. These questions place the burden on disabled people."

The next challenge came from business: "I don't like what I'm hearing. I thought this was supposed to be a

meeting to discuss the issues. That's not what I'm hearing. There is an obvious adversary relationship in the tone of this meeting so far."

So the meeting had begun. Within five minutes, the basic framework of the meeting had changed. Despite plans, the meeting was not going to be a polite discussion. Everyone was taking the gloves off—in one moment, attacking; in another, defending a position.

Certainly, this was no surprise. It was obvious in the manner of the people gathered there, even before the meeting began, that the emotions on both sides ran high. It would have been unrealistic to assume that these disparate groups would not confront each other during the course of the meeting. Their points of view were different—it was bound to happen.

The surprise was that the disagreements surfaced so quickly. Disagreement began before the questions were even discussed—with an argument about the questions.

However, beginning so quickly to speak frankly made it possible to clear the air somewhat. The guard was down—no one was stewing for fear of saying something that wouldn't set well. Very quickly, people became comfortable saying what they felt.

Soon, the questions were accepted as a framework for discussion. Everyone participated at some point; everyone listened at other moments. And, in this process, many things were brought up. Some issues, like the following, were discussed in depth:

Goal and timetables: Representatives of the disabled were in favor of goals, but not timetables, saying that without goals, only people with minor disablilites would be hired.

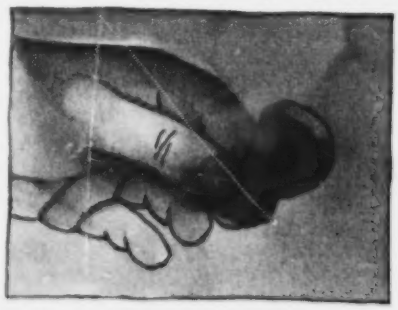
Representatives from business objected, saying that different businesses have different manpower needs. Business felt it was better to consider the individual, matching each individual to an available job.

"Essential functions" of a job: "Essential functions" is not included in Section 503, but Section 504 says a handicapped person is qualified for a job if, with reasonable accommodation, the person can perform the "essential functions" of the job.

Representatives of the handicapped were strong in their support of this approach. They felt "essential functions" let a disabled person know what he/she *must* be able to do. Any other approach, it was felt, penalized handicapped people if they could not perform things which had only marginal relationship to the job.

Business expressed concern about who would do the rest of the job if a disabled person did only "essential functions." How was "essential functions" to be defined? Labor pointed out that, if you make too many modifications, you create a new job which has to be filled.

Pre-employment physicals: This issue challenged a group that was not present at the meeting—medical doctors. Representatives of the disabled emphasized the discriminatory effects of having doctors make recommendations: "Doctors give information to management which is usually not questioned. But doctors don't know anything about a



disabled person's ability to do the job. The doctor's recommendation is based on the medical profession's preconceived prejudices of what a handicapped person is capable of doing. Pre-employment physicals screen people out, not in."

Representatives of business insisted that doctors play a small part in the process—personnel departments have the responsibility of hiring. Business also stated that "if a person isn't hired after a pre-employment exam, he or she can file a complaint, and the burden of proof is on the employer, not the worker."

Labor pointed out that the AFL-CIO gives medical exams only *after* workers are hired, and that physical exams are not needed for sedentary jobs.

Representatives of the handicapped seemed more comfortable with this approach, saying that under Section 504, a handicapped person is offered a job first, subject to a medical exam later. They wanted the same security under Section 503.

Representatives of business continued to disagree, saying Section 503 offered enough protection.

Centralized placement: The discussion of this issue brought about probably the closest thing to a consensus at the meeting. All of the groups could agree that, at the present time, referral of qualified, job-ready, handicapped people is poorly done.

Handicapped representatives insisted that Vocational Rehabilitation doesn't know the job market, and suggested business make use of independent living centers, run by disabled people, for referrals.

Each question sparked an issue for discussion. Each discussion seemed to accentuate the biases of the groups involved. Every bias seemed to reinforce the belief of the adversary that the opponent would never understand.

Finally the meeting was over. And, perhaps, when they left, some took home no more than they came in with. But, in a few hours time it was done—it was all out there on the table. All the questions. All the accusations. All the prejudices.

Whether or not the meeting had any meaning is still open to question. Some felt the meeting had begun as an adversary relationship and had ended the same way. Some saw positive changes in the group—tones that changed from harsh to muted, glimmers of understanding.

But, in the end, it was up to each individual to decide what the meeting meant to him or her. And for each individual, hopefully, within the questions, accusations, and prejudices which were placed upon the table, there was also to be found a kernel or two of truth.

Something that, in time, might bring an individual closer to understanding another's point of view. Probably not yet. This meeting was too much of an encounter. But it was necessary. And it was the right time.

It was, on the day of the meeting, almost the end of winter. In another week, spring would be here. A time for growth. Maybe, in time, a burst of fragrance from black branches.

—Diane Lattin

Knowledge Is Power

Opening Library Doors and Keeping Them Open

Ruth Velleman's book, *Serving Physically Handicapped People: An Information Handbook for All Libraries,* identifies published materials and community resources which will help libraries answer vital questions posed by the disabled concerning their educational, vocational, and rehabilitation needs. In addition, it encourages libraries to commit themselves to the full implementation of Section 504.

The local library, whether public, school, business, university, or special interest, is a traditional resource to which many Americans turn in dealing with their problems.

The following exemplifies instances in which the library community is queried: A visually impaired, elderly man needs social security information—is it available in recorded format? A young working couple is told that their child is mentally retarded—where is the nearest school which offers preschool programs for the child's special needs?

A young college student is losing his sight—where can he obtain his textbooks in recorded format? Does the college library offer electronic visual aids? Does the college have a coordinator for disabled students?

A tradesperson who uses a wheelchair wants to expand his business, and needs to consult the municipal building code—his local library contains these codes, but is the building accessible?

A deaf businessman wants to know particulars about installation of a device for telecommunications for the deaf—who is the local distributor? Is there an *International Telephone Directory of the Deaf* in the public library?

A blind university professor needs a quiet place where he and his reader can consult library reference materials. Does the university library provide such a room? A visually impaired language expert must peruse technical works using an electronic visual aid to determine whether the materials warrant partial or complete taping for his recorded library. Does his agency library own such a device?

A blind lawyer has been hired by the Department of Justice to investigate civil rights infringement cases. Where is the nearest Kurzweil Reading Machine? Has it been programmed for legal language?

These questions reflect some of the information needs of the disabled which can be answered efficiently by a properly functioning library community. Mrs. Velleman's experience as library director at the Human Resources School, Albertson, New York, has been passed on to students attending her workshops and seminars on library service to disabled persons at the Palmer Graduate Library School of Long Island University, C.W. Post Campus, Greenvale, New York.

Many of these students are practicing librarians and have brought current problems in information service delivery to the disabled to her classes. Her book addresses these problems thoroughly and ably. It explores informational needs of the disabled, outlines the role of the librarian in meeting these needs, and offers pertinent sources of information.

Although the book is directed at librarians, members of other disciplines serving the disabled will find that it assembles much information which is useful to them. It is arranged in four parts. Part I, *Introducing Physically Disabled People,* examines attitudes toward the disabled, the media's treatment of the disabled, and emotional and social problems of the disabled.

Part II, *The Public Library,* traces the development of the civil rights movement and its effects on the accessibility of transportation, public buildings, and education programs, and its impact on standards for library service.

Two chapters are devoted to consumer accounts of the library community's provision of special services: Hanan C. Selvin, Ph.D., professor of sociology at the State University of New York at Stony Brook, offers suggestions for improving library services to the blind professional. Alice Hagemeyer, librarian, Service to the Deaf, District of Columbia Public Library, describes her efforts as a consumer and provider to improve library service to the deaf community. An annotated core public library collection is included.

Part III, *The Special Rehabilitation Library,* treats the history and philosophy of rehabilitation, as well as an overview of rehabilitation today. Chapter 11 presents a basic library collection in the fields of medical and vocational rehabilitation which could be used in any type of rehabilitation facility.

Part IV, *School and University Libraries,* gives a history of special education and a thorough description of library services developed to serve the student with special needs. Here again, an annotated core special education collection is given. It covers such areas as mainstreaming, psychology, and sources of instructional materials, which would be helpful to all concerned in treating the disabled child.

Mrs. Velleman has made a fine contribution to the improvement of information services for the disabled in this country. The disabled will benefit not only from the library community's increased awareness of services and programs directed toward their immediate needs, but also from the spread of this information through library contacts with the larger community.

Librarians like myself, who teach also in this specialized area of library service, will use this book as a text so that persons coming into the profession will expect to encounter, or will be prepared to establish, appropriate policies leading to complete accessiblity of libraries to the disabled in this country.

—Grace Lyons

Ms. Lyons is a librarian with the District of Columbia Regional Library for the Blind and Physically Handicapped.

Cerebral Palsy: One Man's Story

I'm blue at times, but along with this there are feelings of happiness with small things; finding more in people than most do. Knowing real inner beauty when I see it brought to light in a smile, in a tease, in a note of understanding. And sometimes, there can be happiness in just watching leaves fall from a tree, or in a magnificent sunset.

I am 46 years old. A hemorrhage at birth left me without control of my nerve center, but with a sound mind. The hardest thing for me to contend with is my poor speech. If only I could communicate better! But I had Mom and Dad, and a sister, too, who gave me lots and lots of love.

My mother's first battle was to see that I obtained an education. At the very least, she wanted me to be able to read. It took patience, it took fortitude, it took endurance, but in the end she managed to pursuade our local school system to find me a home teacher.

My teacher was Mrs. W., a married woman who had children of her own. She never minded my C.P. ways or drooling, but would just sit next to me on the couch with her arm around me to help quiet my overflow of motion. She stayed with me until I obtained a high school diploma . . . marking one of Mom's battles won!

Since Mrs. W. knew of my deep enjoyment of reading, she felt, and rightly too, that good literature would be our goal. Together, we covered everything from Shakespeare, to Dickens, to Winston Churchill. Carefully and thoughtfully, she provided me with the structure to enjoy and understand good literature.

At that time, we did not think that there would be a way for me to write, so we did not go too deeply into spelling. I now

"How does it feel to have C.P.?
Who can really say,
When it's just something
you have to live with,
Twenty-four hours a day."

—Laddie Holt

can write, with a rod attached to my shoe, and much to my sorrow, as I write my poems and articles, many words are misspelled.

My youngest years were my happiest. There was no worry about the years to come, only of the mischief that my sister and I could get into! We had a chemistry set, and spent many afternoons with me directing her to take a pinch of this and a bit of that, concocting dynamite or fireworks. Some of our recipes really worked!

I took great joy in my train sets. I had four of them, with tracks going around a large room. I had a large transformer with push button switches, and my greatest joy was to have a train crash, and watch Mom on her hands and knees, crawling around, putting the wheels back on the tracks.

Yes, I had a happy childhood. I could hippity-hop all over the place like a frog then, but as I grew older, my knees wouldn't take that anymore, so I got a wheelchair. By that time, I had learned to do things in the yard with my Dad. If not always overjoyed with my help, he at least encouraged me to do things as best I could.

For instance, I found ways of wrapping my hands around a rake or hoe to do some work with it. When Dad was cutting down an apple orchard, he fastened a long handle onto a curved pruning saw, and let me cut the trees he had felled into logs we could handle. I got real good at it, and spent a lot of my time sawing away like an ant. Like an ant, just a little at a time, but like an ant, I got the work done.

At 15, I cut myself away from Mother's apron strings. I would no longer stay in my own yard (as frowning neighbors all thought I should!) and became an honorary member of the Sabins Point "Yacht Club." Our neighbor owned a boat yard at the point, and let me go down with him.

He had a junk car lot there also, where he stripped and burned old cars. He would leave me in charge, to watch that none of the kids climbed on them and got hurt. I'd watch the burning cars while he took loads to the scrap yard, calling on adults nearby to help if I needed it.

Things have sure changed down at Sabins Point. There are no longer any old cars, nor any "Yacht Club." But the changes are not all that much to me. Still, grown men come up to me and say, "Hi, Laddie, do you remember me?" Sure, I remember them all (brats!).

This story so far has pointed up to the good side of my life, but now, more than ever, there is worrying too. My mother is 77 now, and still the one to keep our home together. Until she had an operation in 1974, she took care of me herself.

When she had to go to the hospital for the operation, I went to a nursing home for about eight weeks. I shared a room with a quiet elderly man, and it was horrible. I couldn't help banging the sides of my bed, or making a racket when I moved my wheelchair about. I drove him crazy, and he drove me crazy! So, Mother brought me home. We have an aide who comes in every morning, and another who helps me at night, and this arrangement works after a fashion.

If I had a room of my own in a nursing home, I think I could learn to manage, because I have so many ways to keep myself occupied. Talking books, a shortwave scanner, my typewriter and the radio—all of these are a source of pleasure to me. But, all these things cannot be put in a room with two beds. And I cannot be quiet enough to be sure of not bothering an elderly person in the same room.

Because I need to be fed and so forth, nursing homes insist on having me under skilled care nursing. This worries me, since we cannot afford to pay for a private room. Meanwhile, we live from day to day, and are as happy as we can be, thankful for each day that is a reprieve.

A book of my poems is now at the printer's. If it proves of interest, I have others I may be able to do something with. I have been writing poems, or rather, composing them, since I was about seven years old. Mother took them down in longhand each morning when I woke up. She and I have been thankful for this Selectric typewriter, which has no keys to jam together.

I've also been working on a book, but at the rate of typing I have—about two words a minute—it's slow going!

Even today, you may find me down at the water until almost dark. The calmness and tranquility, the setting sun, and even approaching storms, fill me with peace.

Sometimes there is a big oil tanker that slowly plies itself down the bay, coming ever nearer. I can hear a "toot, toot" as some tug comes out to meet it with an answering "toot, toot, toot." Mostly, two tugs will circle a tanker within their own wake before slowly, almost gently, putting their combined noses to glide it up this dog-legged channel into port.

Now comes the sundown with its sunset. As the sun sinks low in the western sky, its rays shine on the rippling water, like golden beams of light. Now, as the last rays of this big red ball of fire set beyond the river and the low hills behind it, the sky behind me darkens, while the sky before me turns to varying shades of reddish pinks, all mixed with white and blue. Magnificent!

The sailboats, their sails furled, have all reentered port. I ask one of my many friends down here to turn my chair light on, and once again head safely home. "Build me straight, O worthy Master!

Staunch and strong, a goodly vessel,
That shall laugh at all disaster,
and with wave and whirlwind wrestle!"

—Longfellow

—Laddie Holt

Mr. Holt is a free-lance writer.

Attitudes: Who, Me?

We hear often about the attitudes of society toward those of us who have been labelled "handicapped." Disabled people are confronted, more often than we like, with a condescending word or look, sometimes ignored, or simply stared at. Sometimes our abilities are doubted because we have a disability. We've learned to live with it.

Disabled people still get mad occasionally, and still fight for equal rights. Sometimes, it's the only way to reach our goals. Other times, it's better to just handle the situation quietly, as best we can, and try not to let it bother us.

But, are non-handicapped people the only ones guilty of discrimination? Are disabled people, in fact, sometimes just as guilty as others? Think about it for a minute.

Have you ever taken the long way around to avoid meeting with or talking to a mentally retarded person just because his or her level of conversational skills is not as developed as yours?

Does being around a blind person make you ill at ease? Make you try to avoid words like "see" and "look" because they can't see or look? Have you avoided deaf people because they're just too much trouble to communicate with?

Have you ever pitied a person who uses a wheelchair because you thought his life couldn't be as interesting or as fulfilling as yours?

If you have answered "yes" to some of these situations, you're not alone. We are all occasionally guilty of poor attitudes.

As a physically handicapped person living in a small town in Delaware, I grew up fairly isolated from other people with disabilities, and was not particularly comfortable with the prospect of meeting any such people. I remained isolated in this respect until my early 20's, when I went to work at an Easter Seal Rehabilitation Center.

There, I gradually met more and more people with various physically handicapping conditions, and we learned from each other. But, I was totally unprepared for the influx of six retarded persons who were to be part of the newly organized activities program at the center.

I was to be Arts and Crafts Director of this program, working with each client individually. I was scared to death! All I really wanted to do was get out of there, and the quicker, the better. I couldn't handle it, or so I thought.

All of these clients were moderately to severely retarded, and most were physically disabled as well. They were "different," and I didn't know how to act, or what to say. It wasn't easy for me, and I actually had to force myself to face these people, and be part of the group. I found that some of their eating habits made me nauseous. I couldn't understand those who had speech impairments, and when one of the clients wanted to be friendly and hugged me, I thought I'd had it for sure!

I had to confront myself with my attitude toward these people, and I really wasn't too proud of what I saw. My conscience began to nag at me. As a disabled person, I knew how it felt to be avoided, ignored, or talked "at." I soon

realized my feelings, and admitted to myself that I, too, had some prejudices to work on. Once I made that admission, it was a little easier for me to deal with my feelings.

I gradually began to relax. I learned that I wasn't the only one who had difficulty with some of our clients' speech patterns. By continuing to listen, I began to recognize some words, and understand gestures.

Even if I did not always understand what a person was trying to say, I learned to make an effort and they were appreciative. I learned not to answer with a placating "yes" when it might have been an entirely inappropriate answer.

When occasionally a client's physical limitations made eating difficult, I learned that it was no sin for me to leave the table for a while to get myself together again. And, a not always appropriate hug and kiss could be diplomatically responded to with a friendly greeting and a handshake. I learned to cope!

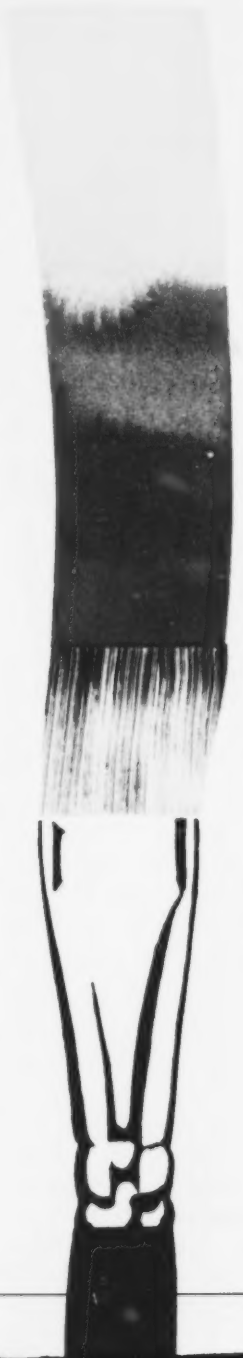
I have been working and playing with physically and mentally handicapped people for 10 years now. I can laugh when I look back, but it was no laughing matter then. From my work in the activity program has grown an awareness of others as individuals with contributions to make, and fine qualities to offer.

This doesn't mean that I have to like every handicapped person I meet, because I sure don't. But I have learned to like or dislike people for what they are, not what they look like, or what they can or cannot do. Handicapped or not, we are all human, and we all make mistakes. But there is the capacity within all of us to recognize our own feelings for what they are, and try to do better the next time.

—Jo Ann Holson

Ms. Holson is the arts and crafts director for the Delmarva Easter Seal Rehabilitation Center in Georgetown, Delaware. The cartoons accompanying this story were drawn by Ms. Holson, and originally printed by the Del-Mar Easter Seal Society.

The Chairman's Column



ART SHOW . . . The Sister Kenny Institute's 17th Annual International Art Show by disabled artists will be held in Minneapolis, Minnesota the week of October 19, 1980. In 1979, over 130 artists from 35 States and 15 foreign countries displayed and sold their work.

The physical requirements for entry are in two categories: Artists who work with brush in mouth, foot or forehead device or artists with disabled hands or arms.

Any medium, including oil, charcoal, pen and ink, pastels, photography, etc., is eligible. Artists may submit more than one entry, and may enter more than one medium. All entries will be judged and displayed, and over $1,000 in prizes will be awarded.

The deadline for entries is August 1, 1980. Disabled artists interested in submitting entries should write for an entry form and further information to: Sandi Gordon, Special Projects Coordinator, Sister Kenny Institute, 2727 Chicago Avenue South, Minneapolis, MN 55407. (612) 874-4463.

NBA MEETING . . . The Canadian National Institute for the Blind will host the National Braille Association (NBA) Meeting in Toronto, Canada, October 20-22, 1980. Braillists and tape transcriptionists from across Canada and the United States will be attending. For more information, contact: Susan Cluff, Canadian National Institute for the Blind, 1929 Bayview Avenue, Toronto, Ontario, Canada, M4G 3E8. (416) 289-2650.

SEXUALITY . . . *Sexuality and Cancer* by Ernest H. Rosenbaum, M.D., and associates, is a new handbook for cancer patients and their families. Practical and supportive, the handbook specifically deals with the sexual problems encountered by cancer patients—dispelling myths about sexuality, the effects of illness on sexuality, special difficulties for those with ostomies, mastectomies, laryngectomies, or cancer of the genital and reproductive organs. Cost: $2.95. Write: Bull Publishing, Book News, P.O. Box 208, Palo Alto, CA 94302. (415) 322-2855.

JOB HUNTER'S KIT . . . The American Association of University Women recently published an excellent resource for women who are job hunting. If you are a reentry woman, a recent college graduate, planning a mid-career job change, or seeking upward mobility, you'll find this kit helpful.

It covers such areas as learning to interview the interviewer, writing a better resume, locating employment options, and avoiding discriminatory hiring practices, as well as other areas, such as how to negotiate salary. Cost: $10.00. To order, write: AAUW Sales Office (JJ32), 2401 Virginia Avenue, N.W., Washington, DC 20037.

504 WORKSHOPS . . . Barrier Free Environments, Inc. (BFE), will hold a series of 10 four-day training and tech-

nical assistance workshops for disabled people residing in North Carolina, South Carolina, Georgia, Florida, Alabama, Mississippi, Louisiana, Arkansas, Oklahoma, Texas, Tennessee, and Kentucky, from June to December, 1980. The project will train approximately 600 disabled individuals in their legal and civil rights under Section 504 of the 1973 Rehabilitation Act, and will provide follow-up assistance.

The training program's objective is to develop a pool of disabled consumers with skills as trainers, negotiators and organizers who will, in turn, educate and support other consumers as well as recipients of federal funds in their rights, responsibilities, and remedies under Section 504. Specific training includes: Instruction in content and scope of Section 504; developing negotiating skills; developing coalitions; and seeking technical assistance.

BFE is attempting to involve the broadest range of disabled people possible in the project, particularly people of every ethnic, racial or minority group. There is no cost to participants selected. Expenses are reimbursed. For more information on exact dates and locations, contact: Cindy Crouse, Assistant Project Director, 504 Training and Technical Assistance Projects, Water Garden, Highway 70 West, P.O. Box 30634, Raleigh, NC 27622. Phone: (toll-free national) (800) 334-5854; North Carolina residents: (800) 662-7409. Both numbers are for both voice and TTY.

INTERPRETERS ... The National Academy of Gallaudet College has published *Interpreter Training: The State of the Art,* developed from a conference of instructors and administrators of interpreter training programs. The document covers the interpreter, the interpreter trainer, policy and administration, and research completed and needed.

It also includes an indexed list of materials used in interpreter training, and an annotated bibliography of over 100 publications for interpreter trainers. Cost: $5.50 (includes postage and handling). Special bulk rates are also available. Send pre-paid orders to: Gallaudet College Press, Kendall Green, Washington, DC 20002. (202) 651-5480.

FOOD STAMP RULES ... Changes have been made in food stamp regulations that will allow elderly and disabled persons to deduct high medical expenses (including attendant care) or exceptionally high shelter costs from their gross income in determining food stamp eligibility.

The new rules allow deductions for monthly medical expenses exceeding $35, and shelter costs exceeding 50 percent of adjusted income. Included in shelter costs are charges for taxes and utilities. The changes in the rules became effective January 1, 1980. Persons who may be affected by these new regulations should contact their local county welfare department for more information.

A GOOD MAN ... Harold Unterberg, our long time friend, and a friend of disabled people everywhere, died February 12 in New York City. Harold had served on the President's Committee for many years. Typically, one of his last official acts as the New York State Advocate for the Disabled was to ensure that people with mobility problems could reach the doors of the Olympic Games at Lake Placid, and be seated where they could see everything.

Harold was a man who loved sharing ideas. When he heard of a good program in another State, he couldn't wait to try it, He generously took the time, too, to show others how to write a better law, conduct a better seminar, or produce a better newsletter. We'll miss him.

CHESS ... The 1977-78 *U.S. Blind Correspondence Chess Champ Tournament Book* is now available at $9.00 per copy. Also, *Castle,* a publication in braille dealing with chess for blind people is available at a subscription rate of $6.00 per year. To order either, write: Gintautas Burba, 30 Snell Street, Brockton, MA 02401.

VOCATIONAL MAINSTREAMING ... is the title of a new book by Winifred Y. Washburn which describes how to integrate learning disabled students into regular vocational education classes. *Vocational Mainstreaming* has chapters on how to teach students who have difficulties in hearing, seeing or speaking accurately. There are also chapters on how to train vocational education staff members and parents. A model prevocational skills course is discussed. The book was written for school administrators, parents, and high school teachers. Cost: $6.00. Write: Academic Therapy Publications, 20 Commercial Boulevard, Novato, CA 94947.

Harold Russell

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Taking Part in the Voting Process . . .
The League of Disabled Voters . . . To Vote Or Not To Vote . . .
Interviews With Congresswoman Gladys Spellman
and Senator Robert Dole

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DISABLED USA

VOL. 3 NO. 8, 1980

What are the opportunities for disabled people to fully join in the selection and election of officials who make the laws and establish programs? In this issue, we learn what is being done and can be done to make disabled people more active in the electoral process.

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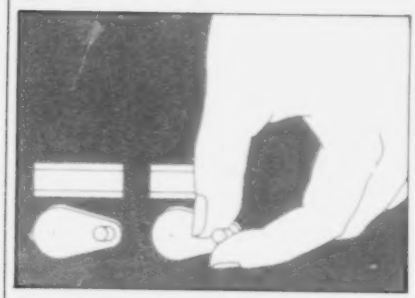

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CHAIRMAN'S COLUMN

PHOTO CREDITS: Pages 14 and 15, Jake McGuire; all other photos, U.S. Department of Labor

Harold Russell, Chairman
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Charles H. Pillard
Diane Lattin, Editor
Lucy Skinner, Program Assistant
Robert Lovelace, Art Director

DISABLED USA reports progress in opportunities for all handicapped workers, keeps Governors' and Community Committees informed of new ideas and activities, and provides all readers with general information concerning developments in rehabilitation and placement of people with disabilities. In a phrase, Disabled USA presents the case for disabled adults.

The Chairman of the President's Committee on Employment of the Handicapped has determined that the publication of this periodical is necessary in the transaction of the public business required by law of this Agency. Use of funds for printing this periodical has been approved by the Director of the Office of Management and Budget through August 15, 1981.

DISABLED USA encourages the submission of articles for publication by all readers, especially disabled people. Articles should be eight to ten, typewritten, doubled-spaced pages, written in an informal style. We also welcome letters from readers for the RSVP column. (All articles appearing in DISABLED USA may be reprinted with or without credit.)

To Vote...Or Not to Vote

Opinion polls keep turning up the fact that increasing numbers of Americans have lost faith in our national institutions.

Each election held in this country continues to demonstrate that one of the "institutions" in which people have lost confidence is the institution of voting.

Well over half of the eligible voters in the United States do not vote in national elections. The turnout for local and State elections is even lower.

Why vote? What's in it for me? These are relatively familiar questions posed by people throughout the country when asked about voting. Are these questions pertinent or appropriate when they come from disabled people, people who are at a crucial stage in their development of an identity as a bona fide minority group? Let's look at some examples.

When the voting age was lowered nationally to 18, there were predictions that the 18-year-old vote would have a significant impact on American political life.

In anticipation of this vote, many areas passed legislation lowering the drinking age (and the age of other "adult" privileges) to 18. Later, when the 18 year olds failed to show up at the polls in significant numbers, many jurisdictions revised the drinking age upward again, since there was no pressure to maintain it at 18.

This illustrates one correlation between voting and issues: A group can be considered powerful and influential on the basis of its anticipated voting strength. If the group does not exercise this strength, it may find that consideration given to its wants and needs becomes nonexistent.

The "black vote," the "Jewish vote," the "Catholic vote," the "blue collar vote" are familiar terms in American media. What lies behind these terms, and what is the reality?

The "Jewish vote" was given credence in the media for Senator Edward Kennedy's victory over President Jimmy Carter in the New York State primary.

The importance of the "black vote" was seen by the media as diminished when no candidate running for President in either of the major parties showed up for a "candidate forum" sponsored by a major national black organization.

The "Catholic vote" has long been considered a power on the issue of abortion, in the eyes of the media. It's not altogether clear whether a "Jewish," "black," or "Catholic" voting bloc really exists, or whether people vote because of other determining factors. For example, educational and income levels are demonstrated factors in who votes and who does not.

The concept of a group as a voting bloc is sometimes more a political perception than a reality. Nevertheless, statistical analyses of who votes and who does not continue to play a major role in the political arena, as seen in such examples as the 18-year-old drinking laws, and the lack of participation by candidates in a national black organization's "candidate forum."

Disabled people have wrested considerable beneficial legislation at local, State and national levels through organizing, lobbying, demonstrating, protesting, and testifying—all the various means that a minority group uses to attract attention and political power.

Disabled people represent every sector of our country, every age and color, race and creed, education and income level. Because there are so few of the unifying and identifying factors which weld together other minority groups, maintaining a political presence on the local, State and national scene calls for continued effort.

An important part of this effort must be the registering, and voting, of disabled people. Accompanying this must be an effort to identify issues important to disabled people, and candidates favorable to the needs of disabled people.

This effort must not be restricted to Presidential campaigns alone. Important as the Office of President is, there are thousands of other offices on State, local, and national levels which are as important to the future of disabled Americans.

Disabled people, their advocates and supporters, must identify issues, support candidates, and, most importantly, vote.

They should vote in every election, work for the candidates of their choice at every level, register disabled voters (and identify ways to sponsor special drives to achieve this objective). They must rally behind campaigns for accessible voting places, and then use these voting places when available, or insist upon alternative ways of voting if they are not available.

Disabled people should run for office at every political level. Stands must be taken and these stands must be supported.

The American political system responds to all kinds of pressure: Oil company pressure, media pressure, labor union pressure, minority group pressure. Disabled people should learn the "pressure points" of the political system, and how to exert pressure to get what they need.

Elected officials listen to the people who vote, who support candidates, work for them, and who push issues. If the disability rights movement is to continue moving forward, disabled people must exercise that most basic right —the right to vote.

—Robert H. Ruffner

Mr Ruffner is the director of Communications for the President's Committee.

Conventions

The national conventions, where the two major political parties in this country transact their internal business and elect their nominees for the offices of President and Vice President of the United States, occur every four years.

Delegates for the conventions are chosen from all over the United States, through either Presidential primaries or State caucuses. Any citizen who has registered for either party is eligible to become a delegate for that party's convention, if selected.

The national conventions are a very important part of the American democratic process. In this story we look at some of the accommodations that are being planned to make these two national conventions accessible to delegates with disabilities.

The Republican National Convention will begin on July 14, at the Joe Louis Arena in Detroit, Michigan. Bob Carter, the Convention manager, pointed out: "The Joe Louis Arena has permanent arrangements for disabled people which mesh into our plans for the Convention. There will be 240 seating places available for people who use wheelchairs."

Eric Gentile, assistant director of the Handicapped Services Program in Lansing, Michigan, voiced both complaints and compliments about the Arena. Gentile uses a wheelchair.

"The primary public entrance is two and a half stories above street level," he explained. "There are two and a half stories of uncovered, unheated cement steps. To get around these steps, a ramp has been built.

"The President's Council on Physical Fitness should give an award to those who can get up that ramp! Two and one half stories of ramp! I'm a paraplegic jock, and I was really huffing and puffing when I got to the top. Maybe those who have power chairs can deal with it.

"There are some accessible doorways on the street level," Gentile continued. "To get from these entrances to the elevator, you have to go through storage areas, the employee area, and the loading docks.

Inside the Arena

"But, the outside contrasts sharply with the provisions inside the building. They've really done a beautiful job in there. The bathrooms are well done, all of them are accessible, and there are large stalls, lowered mirrors, and lowered hand driers. It's beautiful. The telephones, water fountains and fixtures are all excellent."

Gentile elaborated on the seating arrangements: "The seating for people in wheelchairs is interspersed around the arena. People using wheelchairs will not all be lumped in one spot. But unfortunately, our building code does not define "unobstructed seating." The wheelchair seating is unobstructed so long as everyone is sitting down—not on their feet and cheering!"

Cobo Hall, located next to the Arena, will house the support services. Facilities for the press, the caucus rooms, and the staff offices will be located there.

Howard Whitescarver, operations manager of the Civic Center Department, which oversees Cobo Hall, pointed out, "All 50 caucus rooms are accessible. Ramps are built into the curbs, and elevators are available to all floors. Some telephones are lowered, and bathrooms in the major areas are accessible and marked with the accessibility sign."

The Democrats are also working on eliminating barriers at their Convention, which will be held August 11-14, in Madison Square Garden in downtown New York City. The building covers a city block, and seats 20,000 people.

Anthony Avallone, vice president of Operations for the Garden, described arrangements for physical accessibility: "Portable ramps will be installed at the North and South sides of the Seventh Avenue entrance. This will allow disabled people access to the box office lobby.

"An elevator is located in the lobby which reaches the seating area. There are two street level elevators, at the Northeast and Southeast quadrants which are accessible.

Bathrooms

"People using wheelchairs will find the water fountains at comfortable heights. There are accessible bathrooms on each level, and all of them have at least one accessible stall. The international symbol of access will be placed on them by the time of the convention."

However, two people who use wheelchairs, Pat Figeroa from the Center for Independence of the Disabled in New York, and Terry Moakley, director of Barrier Free Design for Eastern Paralyzed Veterans of America, said that when they were at the Garden they could not find accessible bathrooms.

Bill Minnella, a social worker who uses a wheelchair, has filed a suit against the Garden, claiming that they have used discriminatory ticket sales practices and seating arrangements.

Stuart Appelbaum, a lawyer who works for the Democratic National Committee, has been working on physical accessibility of the Convention site.

"We contacted the Garden a while back to find out what arrangements are made to assist people with physical handicaps," he said. "The Garden told us that people using wheelchairs are usually seated on the seventh floor level, where space is available for their comfort. Restrooms are fully equipped with adequate facilities for disabled people.

Support Personnel

"The Garden may also provide supervisory personnel to assist disabled people to their seating area, and insure their comfort. As a matter of fact, on April 23 there was a special performance of the circus for 10,000 handicapped individuals, and the Garden was able to provide for them."

Bill Dixon, the Convention manager of the Democratic National Convention, explained that they have a commitment from the City of New York to provide special vans to transport physically disabled delegates.

This is especially important at Madison Square Garden where, according to Pat Figeroa, "The parking's atrocious. Taxi drivers in New York don't

like to take customers using wheelchairs unless you have someone escorting you.

"And, if you drive yourself, there are two tow trucks just waiting to grab your car if you are gone for five minutes."

Apparently the planners of both conventions are at least thinking about making their conventions physically accessible. Less thought has gone into the needs of blind and deaf people.

Brailled Material

Neither the Joe Louis Arena, nor Madison Square Garden have braille or raised lettering on the elevators for blind participants.

Bill Dixon explained, "We've never had a blind delegate or alternate. If we had one, I'd put a staff person to work on it. We'd consult with experts, and talk to the delegate, and say, 'Hey, what do you need?'

"There's nothing printed during the Convention. We mail the agenda and the final call. The final call is all legalese. I never read it when I was a delegate. I can't think of anything to do for a blind delegate, other than to have a volunteer sit in the seat next to him or her and describe what is going on."

Bob Carter talked about arrangements the Republican National Committee's Arrangements Committee is planning: "We'll meet on the subject of availability of materials for blind and deaf delegates," he stated. "I don't know when. We are not consulting with blind and deaf people, but with people who have run conventions and dealt with these problems."

Interpreters

Neither convention plans to have an interpreter for deaf people on the podium. Neither Bill Dixon nor Bob Carter was familiar with TTY's for the deaf, but, after an explanation, Bob Carter said that he would have a TTY available at the Convention headquarters when it opens on July 7.

Bob Carter explained that the Republican National Convention Committee could not control whether or not the networks interpreted the program for deaf people.

Bill Dixon also explained that he felt access to the Democratic Convention proceedings for the hearing impaired television audience was a network responsibility. He mentioned that his staff had been encouraging the networks to provide interpreters for the Convention.

Apparently, the needs of blind and deaf participants will be given a lower priority than the needs of physically handicapped people. On the other hand, both conventions are being held in large buildings which have become more accessible. This is probably due to the national movement toward barrier free design and the hard work of local disabled advocates.

Dr. Frank Bowe, director of the American Coalition of Citizens with Disabilities (ACCD), stated, "There is a tendency within the convention committees to think about physical barriers when questions of access arise.

Total Accessibility

"This has been an unfortunate problem for some years now, in all areas of the country. The ACCD strongly supports efforts to insure access to the conventions for all disabled people. There are efforts in several States to seat at least some disabled delegates.

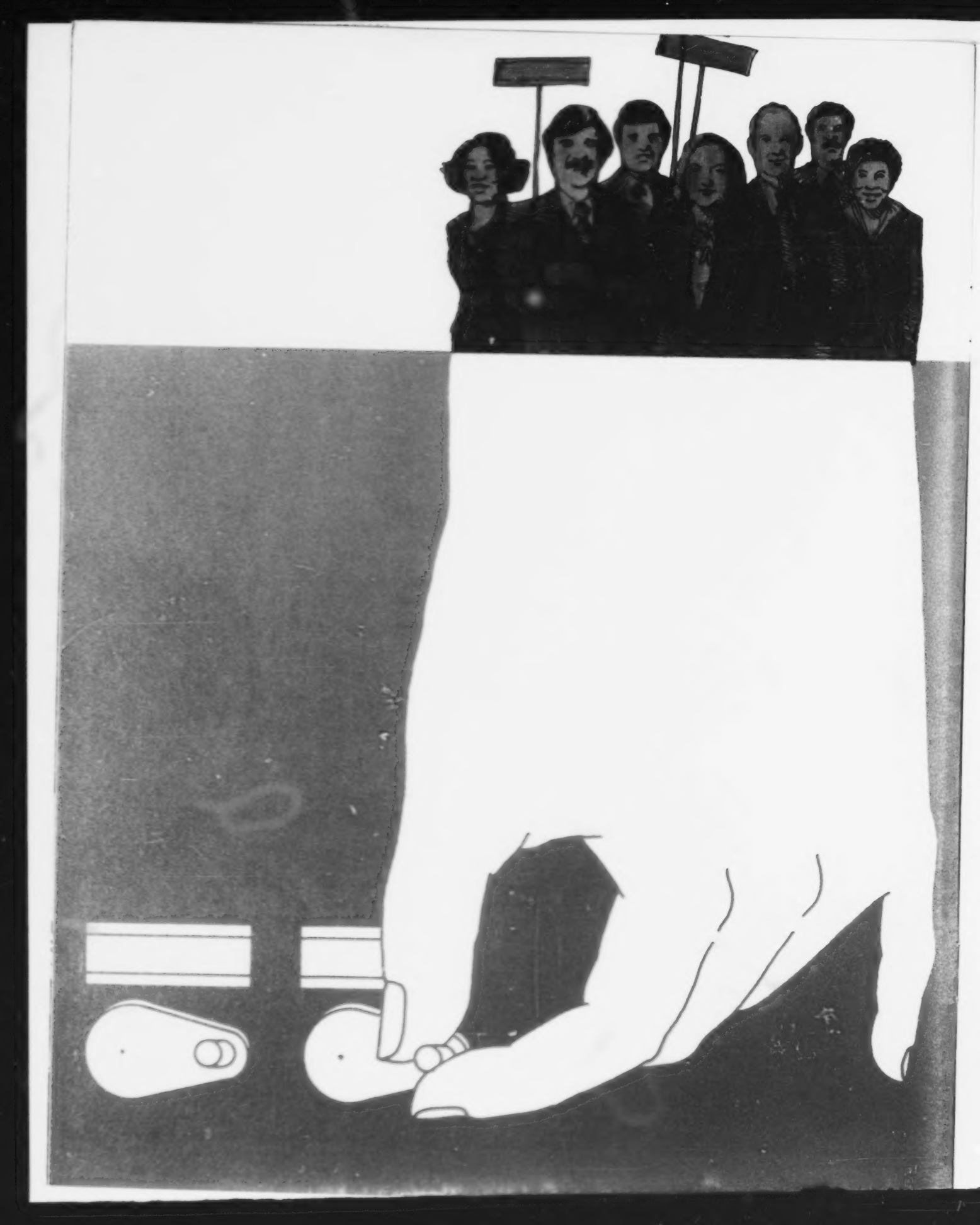
"It is important that the Democrat and Republican parties practice full access to their conventions," Bowe continued. "Such access would illustrate sensitivity by the parties to the civil rights of disabled people, and the importance of disabled people to the political process."

—Dale Brown

Ms. Brown is on the Communications staff of the President's Committee.

Ed. Note: *Neither party has quotas for minority delegates. In their rules, however, both parties have language which encourages States to include minorities in the delegate selection process. The Democrats specifically mention the "physically handicapped."*

The Republicans do not include handicapped people in their list of minority groups. The number of disabled delegates, if any, is not known. However, the question of access to the conventions involves more than accessibility to delegates. It includes invited guests, alternates, and members of the press who may be disabled.



The League of Disabled Voters

During the 1960's, disabled people went through an organizational process, and by the 1970's, had become a formidable pressure group. Now, in the 80's, disabled people are attempting to take their political efforts to another level.

This Spring saw the formation of the League of Disabled Voters. The purpose of the League is to inform disabled voters of the candidates' voting records and outline positions candidates have taken on issues affecting disabled people.

The League will not endorse candidates or parties, but it does plan to issue position papers on specific legislation and policies affecting disabled people.

The League is directed by disabled men and women, but anyone interested in the issues affecting disabled people can join. The group will establish an office in Washington, DC, and, in the beginning, will address itself to federal activities. However, the League has plans to extend itself to the State level in the future.

The organization plans to train persons on how to participate in the political and electoral process. They will conduct seminars to eliminate problems, such as inaccessible polling places, which act as impediments to disabled people in the voting process.

The League will also conduct registration drives, and organize transportation to bring people to the polls on election day.

The ability of the League of Disabled Voters to make the maximum effort in these areas will depend on two things: Funding, and the support they receive from disabled people and the candidates.

Whether or not candidates are responsive to having their views on issues evaluated will depend on how disabled people respond to this information.

More than that, according to League President Eunice Fiorito, the organization will seek funds from members, foundations, and other sources. The ability to raise these funds will determine how effective the group is able to be.

Response to the first activity of the League may give some indication of what lies ahead in gaining political recognition. The League began its work by giving candidates for the Office of President of the United States a detailed questionnaire on disability-related issues. Three of the five major candidates failed to respond by the time the results were to be made public.

Ms. Fiorito stated that "the lack of response (by everyone except Edward Kennedy and George Bush) is blatant evidence that they just don't care about our lives and our concerns."

It may be that such a broad statement is justifiable. Or it may be that this new group has yet to establish itself as truly representative of the 28.5 million disabled Americans the League states are potential voters in the elections.

There is a growing feeling expressed by many people that some organizations of disabled people are not truly representative of the average disabled person. These organizational members are seen as a power elite, well-educated, well integrated. The average disabled person is not seen as having the same level of awareness, nor interest, as the "elite" group.

Perhaps candidates will respond when they feel that many disabled people find value in the League of Disabled Voters. This problem of viability is universal to all groups in the political process, not just handicapped people. In this situation, as in other political confrontations, it is up to the group seeking changes to prove its worth.

In order for the League of Disabled Voters to truly have an impact, it will need the support of disabled people. Ms. Fiorito's sweeping statement about the candidates—"they just don't care about our lives and our concerns"—may be stated again and again in the future.

But, if disabled people don't get involved in organizations like the League, the next time the statement is made, it may be turned around and applied to disabled voters.

—Diane Lattin

For information on how to join, write to the League of Disabled Voters, P.O. Box 23283, L'Enfant Plaza Station, S.W., Washington, DC 20024.

An Interview With Gladys Spellman

> "Each group needs to let us know who they are, what they want . . ."

Gladys Spellman, the Democratic Congresswoman from Maryland's Fifth District, is highly regarded by her disabled constituents. One of the first members of Congress to have a TTY installed in her offices, Spellman has also worked hard to insure that other Congressional and Senate offices provide communications access.

For years, Spellman has had interpreters at her "town meetings," enabling deaf constituents to be full participants in these community events.

She introduced legislation to ensure that hemiplegics receive the same housing benefits granted to other severely disabled veterans, and was successful in having the measure enacted.

Spellman worked to increase funding for programs to educate handicapped children. She voted to appropriate funds for early education of the handicapped and for deaf-blind centers; and she voted for increased budget authority under the Education for All Handicapped Children Act.

Spellman has also continued her efforts to make access to transportation and buildings easier for handicapped and elderly people, sponsoring legislation providing tax incentives for accessible buildings, and measures to require that federal buildings be accessible.

It is an impressive record on paper. But Spellman is not content to do things for disabled people at the legislative level. She is also concerned that disabled people themselves become involved in the process.

And, as a person with a disability who happens to be one of Spellman's constituents, visiting her office, I see that it is not a "paper" record.

As Spellman arrives in the elegant room set aside for visitors to the House of Representatives, she quietly and unobtrusively makes all the correct moves, positioning herself next to the interpreter so that I can watch both of them while she's talking, and addressing her remarks directly to me, rather than the "tell her" or "does she" remarks that less aware people often direct to interpreters.

Spellman is no stranger to dealing with disabled people. And her staff members, also, are comfortable and at ease.

"It's very important," she says, "for disabled people to be aware of their State's delegate selection plan, and for them to compete for district delegate positions.

"But in addition to that," she continues, "people with disabilities need to demonstrate to people running for office that they have the ability to get things done.

"In Presidential and State campaigns, and in campaigns for local offices, there are all sorts of positions to be filled in the campaign offices.

"Offer to type, if that's necessary. But become known to people running for office. Let them know of your concerns and needs. When a candidate gets to know you as a person, it opens doors to the future."

Judy Mannion, a staff assistant to Spellman, offers more insight: "One problem I see," she says, "is that many handicapped groups are not really organized—they are not as well organized as other special interest groups.

"People representing organizations of the disabled need to learn the pressure points, where to go for what they want, and how to push for the things they need. Handicapped people are often shy about approaching a legislator or staff people.

"But, going out and talking to these people is still very important. Communicating the issues and needs to staff members is still something that has to be done on a continuous basis. We have to educate people.

"Let me give you an example," Mannion suggests. "Okay, take the TTY bill for an example. We had to educate the legislators about deafness to help them understand the need for TTYs. We jogged them a little: 'What if a deaf person needed the police or an ambulance? How would they call the police dispatcher?'

"Mrs. Spellman took an MCM on the floor to show the Congresspersons. We had several TTYs on display here, and passed out a lot of literature about TTYs. That's what I mean by educating people. Disabled people need to use this same tactic.

"People with disabilities," Mannion goes on, "must come to us and let us know they're out there, and that they're interested. During Congressional recess, and at the beginning of each new session, experienced lobbyists stop by just to let us know they're still around. They stop by just to talk. It helps us to remember them later on.

"Each group needs to let us know who they are, what they want, and how we can contact them. We cannot ordinarily canvass groups for their opinion, but experienced people know that we count on them to write and let us know their feelings about an issue that comes up."

Gladys Spellman and her staff say things in different ways, use different examples. But the underlying message is clear: Disabled people need to step forward.

Representatives of organizations need to be assertive in introducing themselves, making legislators and staff members aware of their existence, their feelings, and their needs. As Spellman says, 'Become known. Become involved. It will open the doors to the future."

—Muriel Strassler

Ms. Strassler is the former associate editor of "Disabled U.S.A."

An Interview With Senator Dole

"I know disabled people are out there, but I don't know how you're ever going to get the groups and the individuals together. You've got the ear people and the kidney people and the paraplegics."

The words are those of U.S. Senator Bob Dole, the Kansas Republican who, until mid-March was a candidate for his party's Presidential nomination.

Disabled himself by a serious wound sustained in World War II, Dole achieved national recognition as President Ford's running mate in 1976, and has long been identified with the rights and opportunities of America's handicapped people.

During his own bid for the Presidency, he was quoted in the *Washington Post* as saying he hoped to build his effort, at least in part, on a constituency of "farmers and disabled people."

To Dole, the handicapped are a constituency, but one which has historically failed to maximize its impact on the political process. In a recent interview in his Capitol Hill office, he suggested some of the problems and some of the potential that he sees in the movement to organize the 30 million Americans who have disabilities.

"It seems to me," he explained, "that disabled people *are* a special interest group—maybe it would be more precise to say a group in which we should have a special interest.

"There should be some way to do it, because disability cuts across party

> "Generally, it's some 'whole' person they send to Capitol Hill."

lines, it cuts across ethnic lines, it cuts across color lines. It's larger than the traditional party structure, yet to date, it has remained a sleeping giant.

"They're out there," Dole said of disabled people, "and they ought to be in the mainstream, participating. That may sound selfish when a politician like me says it. I don't know about the Democratic Party, but in our Party there hasn't been any real effort made to start a dialogue with all these millions of people."

A former National Chairman of the GOP, Dole speaks from authority when he expresses concern about the relationship between America's politicians and her handicapped citizens.

"I've asked questions as I've gone around the country, questions like, 'How many disabled people are here in this meeting tonight?' Well, not everybody is going to stand up or roll their wheelchair out into the aisle; but you know from watching the door that there aren't any to begin with. It's hard enough to see from a practical political standpoint . . . when you think of your own involvement in the issue, your own special relationship, then it practically breaks your heart."

When asked about the role of disabled people in his bid for the Republican presidential nomination, Dole cited two examples to prove his contention that, in politics, "disabled people can be quite successful."

"My chairman in one of the New England States, a man in a wheelchair who holds a State office himself, put together an effective campaign when he was running himself. However, things came to such a pass in our campaign that he quit in disgust," he said, smiling wryly. "One of my leaders in Florida, in the Tampa area, was a woman who uses a wheelchair, so I know some disabled people are out there and working effectively in politics."

Regarding the upcoming Presidential election, Dole focused his attention on party platforms. "There ought to be some way to get the attention of the Democrats and the Republicans, either at the platform hearings or somewhere else along the line. I certainly hope disabled people have gotten themselves organized enough to have an impact on the party platforms.

"The main thing is that they be active, whether they're Democrats, Republicans or Independents. They should be where they have the most strength. They should speak up as loudly and persistently as anyone else—but the key is organization."

Senator Dole made the telling point that disabled people are involved in politics already, although in ways that do not always serve their own best interests. "The politics within different groups of disabled people make our two-party system look tame.

"About 10 years ago I decided that we were always talking about handicapped and disabled persons and what we ought to be doing. The fact is, we were talking more than we were acting, and we hadn't really developed a cohesive or united front among the various groups. So, once when I was getting ready to make a speech on the floor of the Senate, I asked all the different disability interest groups from around town to get together.

"What happened next was a textbook illustration of the problems affecting the politics of disability. Some had never met each other. It was as if they had been saying, 'I'm dealing with hearts, not kidneys, and I don't want anybody messing around with this heart area. This is my constituency, and I don't want you trying to invade it.' I can understand that—it's called politics, but I don't know if it's good for disabled people."

Dole stresses the need for disabled people to come of age politically. "Having disabled people get elected to office is very important, if only for awareness. For example, right now Nancy Kassenbaum is the only woman in the Senate. Well, there should be 25 more—and some people say 50 more, which would give women all the power." He smiled. "It's a lot like that for disabled people.

"Strangely enough, we find that many of the 'lobbyists' for different disability groups aren't handicapped themselves. If a group doesn't have enough confidence to have one of its own up front saying, 'We're here for the whatever-it-is,' it really blunts their impact. Yet that's often the case. Generally, it's some 'whole' person they send to Capitol Hill."

Dole professes to see some optimistic signs. "I think the transition to disabled people representing themselves is coming of age. Now there's some kind of evolution. Disabled people have been through it and they understand it. The able-bodied person can be outstanding in his or her own way, but isn't the same. An individual with a cause or an experience can state the case better than anybody else."

In closing, Dole reiterated, "Disabled people are out there. I just don't know how we'll get in contact to put it all together with them politically."

Looking back, it seems that Dole may have said more than he knew. If an experienced politician with a personal interest in disabled people and a commitment to their political activity and well-being—on either side of the party line—doesn't know how we're going to get it together politically, that says something. It says that disabled people must overcome the tendency to protect "our territory" and we must quit our own political infighting.

It means we have to come forward and be willing to get involved. In this election year, we have to start making enough moves and changes so that in two years, or four years, no politician will wonder where we are.

Senator Dole, your message came through loud and clear.

—Lynn Park

Ms. Park is on the Communications staff of the President's Committee.

Voting: An Overview

Every day, disabled people routinely face architectural and communication barriers. But there is one activity that doesn't happen every day, that is commonly held to be an inalienable right for all Americans. It is voting.

Just as disabled people are excluded and discouraged from participating in everyday activities by obstacles at the store, the bank, or the sports arena, so too are they often discouraged from voting by barriers at the ballot box. In this story we discuss some of the obstacles disabled people can encounter at the polls, and some measures which may allow more and more of us to exercise this basic right.

In many instances in the past—and sometimes in the present—polling places have been located in older buildings, such as school buildings with flights of stairs.

In addition, some disabled people cannot manage the physical manipulations necessary to operate a voting machine. And blind people are sometimes required to take a poll worker, rather than a person of their own choosing, with them into the voting booth.

Absentee Voting

Absentee voting is one option. Provisions are sometimes made—and sometimes not—to allow disabled peo-

ple to cast absentee ballots. The problem with this option is that it means foreclosing on one's options several days before an election.

Opinion polls repeatedly show that many people regularly exercise their right to change their minds right up to the last minute—sometimes on the basis of late-breaking news. Thus, absentee voting is not an ideal option for disabled people by any means.

In recent years, several politicians have begun giving serious thought to these problems. Most recently, Senators William Cohen (R-Me.) and Birch Bayh (D-Ind.) have introduced legislation in the Senate to "provide that polling registration places for elections for federal office be accessible to physically handicapped and elderly individuals."

"Voting Rights Act"

Cited as the "Voting Rights for the Elderly and the Handicapped Act," this isn't just a pie-in-the-sky piece of legislation. Rather, it's a measure with teeth in it—or will be once it is enacted into law.

Provisions of the Act come under three main categories:

The first is the selection of polling and registration places. It deals generally with physical accessibility. Buildings should provide access, by ramp or other means, to people in wheelchairs, and the actual location used in the building should be on the first floor or accessible by elevator.

The second provision deals broadly with alternative means of voting in instances where a facility cannot be located to meet the requirements of the first provision.

There are two main options: Selection of one or more alternative polling places outside the voting precinct (but within the same congressional district) to which disabled people not able to use the inaccessible site may be assigned, or use of absentee or curbside voting procedures.

The third provision applies whether or not a site is physically accessible. It requires that paper ballots be made available at all polling places for the use of voters unable to operate a voting machine. Adequate written instructions must also be posted so that deaf persons have information on how and where they may register or vote.

For blind people and for those unable to use either a voting machine or a paper ballot, the guarantee is made that they may be accompanied into the voting booth by a person of their own choice to assist them in the completion of their ballot.

Enforcement

These, in brief, are the provisions of this Act. The teeth come from the enforcement powers given to the U.S. Attorney General.

Whenever there is cause to believe that any State or political subdivision has not complied with these provisions, he has the option of instituting, "in the name of the United States, any actions in a district court of the United States against the State or political subdivision, including actions for injunctive relief, as he may determine necessary to implement this Act."

The consequences of this kind of action could be legal steps to ensure these voting rights.

If enacted into law, this bill will guarantee physically disabled people both access, and greater ease, of voting in federal elections. It also stands to reason that access to local and State elections will be facilitated, once jurisdictions discover that the provisions are neither impossible nor onerous to fulfill.

Press Conference

Attention was drawn to this bill late in 1977, when several Congresspeople held a press conference at a Washington, DC, polling place located in a church just a few blocks from the Capitol.

When one young woman in a wheelchair saw the steep flight of exterior steps to the polls, she said, "With my bone condition that's just too risky. I know that the people helping me are careful, but a misstep could land me in the hospital for months." This comment, and others like it, made an impression on then-Congressman Cohen.

Sometime later, when he moved across to the Senate side of the Congress, Senator Cohen resolved to take renewed action on this issue. The result was the bill discussed here. Introduced with bipartisan support, it was referred to the Rules Committee, which held hearings late in October 1979.

Witnesses gave testimony on the benefits of such an Act, and on the possible problems that would have to be resolved. Those present included a disabled federal employee; representatives of organizations for veterans, blind people, and elderly persons; and State election officials.

New Language

Now, some months later, the Rules Committee and Senate staff workers are refining the language of the bill. One item under particular discussion is the absentee ballot provision, to insure that it is not used to avoid fulfilling the intent of the Act as regards physical accessibility. When new language is agreed to by the sponsors of the legislation, the Rules Committee may reopen hearings to obtain further reactions from State election officials.

It is hoped that the Voting Rights for the Elderly and the Handicapped Act will pass soon. This will mean acceptance by the Senate, approval in the House of Representatives, and the President's signature. The precise legislative strategy has not been determined, but sponsors hope for quick action.

Outcome Uncertain

This process—that of following a good idea as it becomes a bill that may or may not become law—is long, slow, and often frustratingly complex. The final outcome is uncertain, though key staff people feel that it will eventually pass.

When that happens, disabled people will have gained one more, very vital, tool to help them implement their full citizenship.

Readers interested in learning more about the Voting Rights for the Elderly and the Handicapped Act can write to the sponsors of the legislation: Senator Birch Bayh, 363 Russell Senate Office Building, Washington, DC 20510, and Senator William Cohen, 1251 Dirksen Senate Office Building, Washington, DC 20510.

—Lynn Park

Ms. Park is on the Communications staff of the President's Committee.

Voting Viewpoints

John Chappell is the president of Handicaps Unlimited, a Virginia organization. He uses a wheelchair. "I've never been assigned to an accessible polling place," he remarked. "The last Presidential election was typical. First, I had to find a place to park where I could get out of my car. Then there was a curb before I could get onto the sidewalk.

"When I finally got to the building where the voting took place, there were two more steps, which I had to ask people to help me up." Once he cast his ballot, of course, he had to go through the whole procedure again to get back to his car.

Chappell's experience is probably typical for voters who have mobility limitations. If you want to vote badly enough, you have to map out a strategy to get to the polling place, and allow yourself to be carted up and down stairs if there are no accommodations for access.

Louis Rigdon

Louis Rigdon, a lawyer with the Criminal Division of the Department of Justice, has voted in every election in the past 25 years. He also uses a wheelchair. Casting his ballot is no easy matter.

A cab driver takes him to the driveway behind the church which is his designated polling place. Rigdon is then pushed up a sidewalk for 25 feet, then down a 20-foot incline, which leads to the church entrance. Ten steps block the basement, which is where voting takes place.

The cab driver goes down the steps and informs the polling manager that Rigdon is there to vote. She goes out and takes him forms which he fills out with his name and address. She goes back, checks to make sure that he is registered, then brings him a ballot.

Rigdon fills out his ballot at the top of the steps. "It's not exactly a secret ballot," he says wryly. "People come up and ask questions, make comments, and otherwise engage in conversations with me while I fill out my ballot!

"The poll manager knows me well now," he continued. "We have worked out a convenient way to deal with the inaccessibility situation. Still, I am treated essentially in a segregated manner. I am stopped at the doorway. I'd like to have an accessible polling place where I could go and vote by myself without receiving the assistance that I now require."

Julie Rogers, a speech pathologist at Ohio State University, who also uses a wheelchair, commented: "I vote in an elementary school where there are steps that lead to the front entrance. When they see me coming they get the janitor to open a side door, which is kept locked. It's accessible, once the door is unlocked.

"I do know some people who have experienced problems. But usually, when they are discovered by the Board of Elections, arrangements are made to deal with these problems.

"For example, there was a Vietnam veteran who uses a wheelchair. In the last election, he went to a school which is his polling place, got out of his van, and went to the bottom of the steps. He couldn't get up the steps alone.

"Well, an official working at the polls told him that if he couldn't get inside, he shouldn't try to vote, and should vote by absentee ballot the next year. The vet called me, and I called the Governor's Committee. Two hours after I made my phone call, people from the Board of Elections were at his home, so that he could cast his ballot!"

Not all polling places, of course, are inaccessible. Dick Heddinger, a mathematical statistician at the Department of Energy, uses a wheelchair and has never had problems getting to his polling place in Bowie, Maryland.

"Our community is fairly accessible," Heddinger noted, "but I did vote by absentee ballot last year, because I was in California during the elections."

Before voting, one must register, and places to register are not always ac-

cessible either. For example, registration workers had to meet John Chappell at his car so he could fill out the required forms.

On the other hand, programs targeted to register voters often reach disabled people. Rick Benson, who lives in Montgomery County, Maryland, registered while he was shopping in a mall. "They just came up to me and said, 'Will you register?' So, I registered.

"I'm voting in the next election. The place where I'll vote is near my apartment, on the first floor of a building, so I'll need only to get up over the curb. With so many people there, I don't think it will be a problem to get some help over the curb."

John Resinger

John Resinger, a student at Kennedy High School, also in Montgomery County, Maryland, was also reached by a registration drive. "Some people from the Student Government Association came to one of my classes with forms, and asked if anyone was 18 or older. I was, and I filled out the form. I don't know if my polling place is accessible or not, but around election time, I'll look into it."

Matt Zehner registered to vote last year. He is also a student at Kennedy High School, and has multiple handicaps, including hydrocephalus, a slight paralysis on his right side, and a pinched nerve which causes a back and forth movement of his head.

For Zehner, and for many other people with sensory and emotional handicaps, the complexity of registering and voting can be a barrier.

"My mother helped me," Zehner explained. "I went over the form with her. Without her help, though, I would have gotten confused with which district to register in, and how to answer some of the other questions on the form.

"Back in junior high school, I did study how to vote, but I got confused by all those buttons on the machine. I plan to ask for help from election officials."

Not only is the voting booth complicated, but the names of the candidates are written down, making the sense of sight necessary. How do people with visual problems vote?

Donna Eggert

Donna Eggert, staff assistant for the American Council of the Blind, explained her method: "I go into the poll with someone I trust who pushes the buttons for me. If I can't find someone I trust who is able to come with me at the particular time I want to vote, I call the headquarters of the main candidate I want to win, and ask them to push the buttons for me. That way, I know they won't push the wrong buttons!

"I think it's disgusting that I have to take someone into the booth with me," Eggert continued. "I don't have the same privacy other people do. I feel it's a discrimination against me as a disabled voter. But, I also think it's important for me to vote."

Roger Petersen, an administrator for a program designed to help young people, is also blind. He usually brings his son along to help cast his ballot. If his son is busy, Petersen pays a reader.

"I think you could make a voting machine that would be accessible to hearing, visually, and perceptually impaired people," he said.

"But I also feel it would need to be a videotape presentation of the candidate.

Roger Peterson

You'd see a picture of him and his name written out. At the same time, you'd hear a voice stating his name and party affiliation. Then you'd go over all the choices and execute some keypunch to vote the way you want."

John Chappell commented, "It might be logical to provide braille markings or a recording that would state which candidate was which. If the machine was designed with these options, it wouldn't be a problem to add them on when needed."

Disabled people face many obstacles when they want to vote. Some even have to pay for the privilege. Rigdon's cab driver, for example, charges more for the extra services he provides, and Petersen's reader also costs money. Handicapped people also generally spend more time at the procedure of voting than the average citizen.

Is it any wonder that some disabled people don't bother to vote? As I interviewed people for this article, I found that the majority of the people I talked with had never voted before.

Comments ranged from, "Well, there's no one I like to vote for anyway," to "I just don't care about voting."

Is this attitude because of the many barriers placed in their way? Or are they just like the thousands of American citizens who are apathetic and uncaring?

These are important questions; questions that disabled people themselves must confront and answer.

—Dale Brown

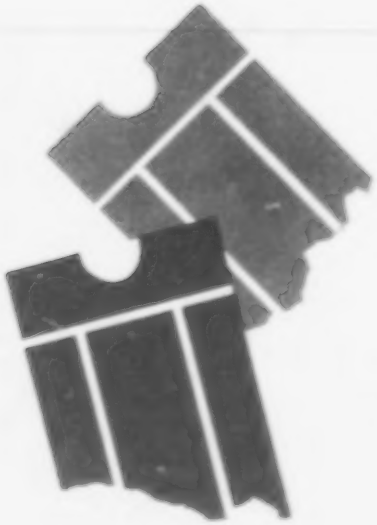
Ms. Brown is on the Communications staff of the President's Committee.

the Chairman's Column

FOR WRITERS . . . *Disabled Writers Quarterly* is seeking prose fiction of all types (particularly short stories, poems, novellas, and plays) for its first issue.

Autobiographical or personal fiction will be particularly highlighted in this new literary magazine, whose aim is to encourage physically disabled people throughout the English-speaking world to write for publication.

Persons interested in submitting manuscripts should contact Samuel M. Miller, Editor, 2495 Major Street, St. Laurent, Montreal, Quebec, Canada H4M 1E5.



CAPITAL IDEA . . . The Capital Centre in Landover, Maryland, is the home of the Washington Bullets basketball team and the Washington Capitals hockey team. It is a large arena which also accommodates rock concerts and special events such as the International Horse Show.

Since its opening, the Capital Centre has had special parking and seating on the Concourse level, which is fully accessible for disabled people and their friends. This seating is available on a first come, first served basis with the general public. However, recently the Centre has agreed to hold 20 seats until showtime for disabled people.

Capital Centre has also agreed to assist disabled people when they purchase tickets for concerts on the arena floor. The Centre staff will arrange for ticket holders to get accessible seating on the floor. These ticket purchases can be made at any Capital Centre ticket outlet.

For other events the Centre will, whenever possible, try to make arrangements for handicapped persons to be seated on the floor level. This arrangement can be made by contacting Gary Handleman, director of administrative operations, at (301) 350-3400. Other inquiries can be directed to Handleman at this number.

BRAILLE TTY . . . The new Department of Education (ED) has acquired a Print-Braille TTY machine that will allow blind or deaf-blind officials to communicate with deaf or deaf-blind individuals. The machine enables the typed messages sent or received to be typed simultaneously in print and braille.

Located in the Office of Handicapped Concerns, which has the mission of linking the priorities and needs of handicapped citizens to the policies and practices of the Department of Education, the Braille TTY will enable the blind director of the Office of Handicapped Concerns, Chet Avery, to communicate by TTY.

The Braille TTY was developed by Lee Brodie, Phone-TTY, Inc., who has installed more than 25 of these machines throughout the country. For further information, contact Lee Brodie at Phone-TTY, Inc., 14-25 Plaza Road, Room 316, Fairlawn, NJ 07410. (201) 795-5414 (Voice and TTY).

The address and phone number for the Office of Handicapped Concerns is Office of Handicapped Concerns, Room 4129, FOB 6, 400 Maryland Avenue, S.W., Washington, DC 20202. (202) 245-0873 (Voice) or (202) 472-3731 (TTY).

BRAILLE BIBLE CLASS . . . Anyone interested is welcome to participate in a taped Braille Bible Class by mail. Your questions and comments become part of each class tape. For information, write in braille or ink to: Braille Bible Class, College Hill Presbyterian Church, 5742 Hamilton Avenue, Cincinnati, OH 45224.

TRAVELING? . . . Physically disabled and planning a trip? Worried about finding accessible hotels and tourist attractions? For people with disabilities, travel can be troublesome without good advance planning. A free service of the Moss Rehabilitation Hospital now provides information for the disabled traveler.

The Moss Travel Information Center helps disabled people throughout the United States plan their trips for here and abroad. Located in Philadelphia, the Center includes an extensive collection of data on such topics as accessible restaurants, airplane regulations, cruises for disabled people, and accessible cultural facilities.

Unlike a travel booking agency, the Center provides the information disabled people need to plan their *own* excursions. Requests should be specific and include an outline of cities or areas travelers want to visit, as well as the kinds of tourist attractions they are interested in.

The Travel Center then responds by sending appropriate available information, including the names of people or agencies who can provide further information. Write or call: Travel Information Center, Moss Rehabilitation Hospital, 12th Street and Tabor Road, Philadelphia, PA 19141. (215) 329-5715.

AFFIRMATIVE ACTION . . .
According to a recent news release from the Disabled American Veterans (DAV), the 663,000-member group has renewed charges that affirmative action programs for disabled and Vietnam-era veterans are not being adequately enforced by the U.S. Department of Labor.

Under federal law, any firm doing more than $10,000 in business with the federal government must list available job openings with State employment service offices, where operations are overseen by the Labor Department.

The employment service office is then required to give disabled and Vietnam-era veterans priority in referrals to these jobs. In turn, employers are required to take affirmative action to employ and advance these veterans.

During fiscal year 1979, employers listed 1.2 million jobs with State employment services offices. Only 3,254—or 0.3 percent—of these jobs were given to disabled veterans. Vietnam-era veterans received only 41,500—or 3.5 percent—of these jobs. The figures show very little variation since 1975, according to DAV National Employment Director, Ron Drach.

Harold Russell

THE PRESIDENT'S COMMITTEE
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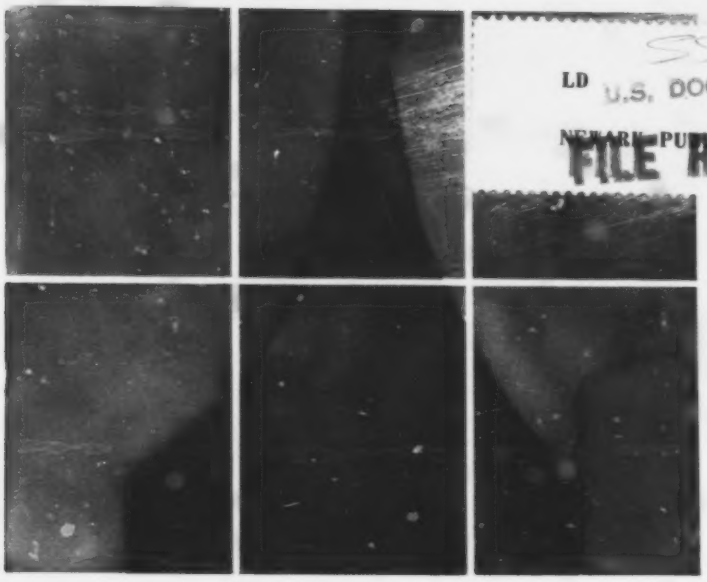

Where Disabled People Live: Adaptable Housing . . . Sheltered Homes . . . Special Projects—Plus: Legislation to Eliminate Work Disincentives . . . Handicapped American of the Year

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DISABLEDUSA

VOL. 3 NO. 10, 1980

Wherever we live, we all like to believe our home is someplace special. Most disabled people will never live in a truly grand manner, but new programs offer better facilities than ever before. For some. For others, the future will be much the same as the past.

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DISABLED USA reports progress in opportunities for all handicapped workers, keeps Governors' and Community Committees informed of new ideas and activities, and provides all readers with general information concerning developments in rehabilitation and placement of people with disabilities. In a phrase, Disabled USA presents the case for disabled adults.

The Chairman of the President's Committee on Employment of the Handicapped has determined that the publication of this periodical is necessary in the transaction of the public business required by law of this Agency. Use of funds for printing this periodical has been approved by the Director of the Office of Management and Budget through August 15, 1981.

DISABLED USA encourages the submission of articles for publication by all readers, especially disabled people. Articles should be eight to ten, typewritten, doubled-spaced pages, written in an informal style. We also welcome letters from readers for the RSVP column. (All articles appearing in DISABLED USA may be reprinted with or without credit.)

Magruder's Discovery:

New HUD Project Includes Adaptable Apartments

Randy Halfant, a 26-year-old, brown-haired woman, just moved into a new garden apartment. "I like it very much," she stated. "It's very accessible. My old apartment had stairs. I had to take one step at a time, and it was quite painful.

"It's easier here. Light switches are at a level where you can reach them and they have switches at both ends of the room, so you don't have to walk across it. The carpet is easy to walk on, too.

"Even though I'm not in a wheelchair, which is what the apartment was designed for, I have partial paralysis of the right leg and arthritis of both knees. I have trouble bending my knees, and I like having everything at a level where I can reach it."

Halfant lives in Magruder's Discovery, a complex of 134 contemporary garden apartments, located in Bethesda, Maryland, a wealthy suburban area. The apartment in which she lives is unique.

Her unit and the one across from it were designed as models for a research project which explored the cost and marketability of housing for

disabled people. Each home constructed for this project conformed to the new residential accessibility specifications recently developed by the American National Standards Institute. (See story on page 6.)

These homes were designed to be adaptable as well as accessible. An adaptable home can be easily used by non-disabled and disabled people. These homes with few modifications, if any, could easily be sold to non-disabled buyers.

The study was funded by a grant from the Department of Housing and Urban Development (HUD) to the National Association of Home Builder's (NAHB) Research Foundation. According to Steve Moore, chief designer of the two apartments at Magruder's Discovery, the Foundation was chosen as the recipient of the grant because of its experience with different types of buildings.

"We could get the information we needed," Moore stated. Other research projects included a cost-busting house which demonstrated inexpensive building techniques and "an energy efficient residence."

"Doing a project in the area of disability was new to us," admitted Moore. "We did nine months of library research and interviews with experts before we even began."

In search for adaptable floor plans, different types of building materials were used. The apartments in Magruder's Discovery were made of wood. Two similar ones in Miami, Florida, were constructed from cement. Two adaptable private homes were also built, one in Las Vegas, Nevada, and one in Denver, Colorado.

These two Bethesda, Maryland, "adaptable" apartments are located within a Section 8 project built by HUD for low income persons. Residents may not be charged rent higher than one-fourth of their income. The two special apartments are included in the housing complex as part of the ten percent which must be made accessible for disabled people.

The requirement is one of the main reasons why HUD is interested in cost effective, adaptable housing. At Magruder's Discovery, ten units, in addition to the special units, are accessible to handicapped people.

Accessibility to Halfant's apartment begins even before the entrance. Large parking spaces for handicapped people are provided. The sidewalks are wide enough to accommodate a wheelchair easily.

Most sidewalks are higher on one side to allow rain to flow into the gutter. This slant tends to make wheelchairs roll into the street. Halfant's sidewalks slant only slightly, making it easier for a wheelchair to maneuver.

All the entrances to the apartment building have ramps. The front door to Halfant's apartment is wide and the keyhole is lowered. The sliding doors in the apartment are large enough to allow a wheelchair to pass, and they also have easy-to-grasp, lever handles. In addition, all the hallways throughout the building are wide.

The rug, which Halfant found easy to walk on, was designed to produce the least friction for wheelchair tires. The kitchen and bathroom tile, however, produce slightly more friction, so that the wheelchair tires do not slip.

Along with the electric light switches, the plugs in the apartment can also be reached by people in wheelchairs. Even the thermostat and

the switches for the garbage disposal and range hood fan are at easy-to-reach locations. In addition, the handles for opening windows are adjustable.

The entire kitchen is designed to make work easy for individuals who use wheelchairs. Cabinets, counters, pantry shelves, and the sink are adjustable in height.

A person in a wheelchair can slide under the sink safely because the pipes are insulated and are arranged so that they are out of the way. Because of this, the disposal is next to the sink in a separate trough, with the switch in front of it, rather than on the wall.

The freezer is at the left half of the refrigerator, rather than on top. In addition, cabinet fronts are removable to allow easy access for wheelchair users.

The bathroom in the apartment is also designed for accessibility. It's a large room with a vanity, having an open end, also easy to slide under.

The shower is also bigger and Halfant commented, "I like the shower, because it has a seat in it, for when you get tired of standing." For a person who uses a wheelchair, such a seat is necessary.

Another accessible feature of the bathroom is the shower head which is adjustable in height, and can be hand held. A special anti-scald control unit balances the water temperature and makes it impossible for someone to burn themselves.

Change in water temperature can occur when there is interference from another appliance (i.e. toilet being flushed, dishwater turned on). This anti-scald unit is an important feature for people with paralyzed limbs who do not feel the heat, and might otherwise get burned.

The walls around the toilet and shower have blocking (plywood), so that the tenant can place grab bars where they are needed. One of the demonstration apartments had a raised toilet which was hotly criticized by a quadriplegic man who asked that his name not be mentioned.

"Raised toilets are not useful to that many disabled people," he explained. "As a matter of fact, I would have preferred to have less room in the

bathroom and more room in the bedroom. You have to do a three-point turn to get into one of the bedrooms, and I can't maneuver in the kitchen too well.

"I really resent the fact that they are tooting their horn about this being model housing for the crippled, when there are so many problems."

Because of the shortcomings he found in the special units, this man chose to live in a standard apartment. (Standard apartments are provided for disabled people by Housing and Urban Development, along with the adaptable housing units.) Halfant, however, is basically pleased with her adaptable housing unit.

"Accessibility to the outside is great," explained Halfant. "I walk right out the door, and I have the trashroom, the laundry room, and the storage area on the same floor. They have sliding glass doors which are terrific. They make it easy to carry things in and out."

But Halfant also had a complaint: "Their mail boxes are up eight steps. Although it is difficult for me, I can get my mail, but someone in a wheelchair would be up a creek without a paddle. I'm sure they just overlooked that fact.

"However, that is the only time I have to walk up and down stairs where I live. Therefore, my knees are less painful, and I am not as drained. I have more energy. Also, it's easier for me to clean the apartment and get around. So, I have more time to do what I want, like enjoy the outdoors, swim, and visit friends."

It would seem like the adaptable housing is not suitable to everyone. And a few blatant errors, like inaccessible mail boxes, certainly need correction. But the concept of having adaptable housing for disabled people as part of regular housing projects is a positive step.

For further information about the house in Las Vegas, Nevada, or a similar one to be constructed in Denver, Colorado, contact Grant Skinkle, NAHB Research Foundation, Inc., Box 1672, Rockville, MD 20850. Phone: (301) 762-4200.

To find out more about the apartments at Magruder's Discovery contact Steve Moore at the same address and phone number.

—Dale Brown

Ms. Brown is on the Communications staff of the President's Committee.

Is There a Housing Market?

Finding a home in the Washington, DC, area is no easy task, especially if you're physically disabled and require special accommodations. When "The Washington Post" printed an article on January 5, 1979, about a house for sale which included special features for people in wheelchairs, it appeared to be an answer to housing problems for some disabled people. At the very least, it indicated a recognition of disabled people as potential homeowners.

Now, we thought it would be interesting to check on what happened. Did disabled people respond? Had more homes been built and sold?

The model home which the "Post" wrote about (and which is pictured here), was described by the paper as, "a one-story house with special features for physically handicapped persons. Built by Oakridge Housing Corp. . . . the house, adapted for a handicapped occupant, has wide hallways, an over-sized bathroom, and handgrips on doors. The vanity sink has room for a wheelchair to be rolled close to it. The house can be built with two, three, or four bedrooms."

The design of the home appeared to be well thought out. It was entered in a competition sponsored by "Family Living" magazine, and it won an award.

Norman Zaret, who heads Oakridge Housing Corporation, stated that he got the idea to build a home which accommodates handicapped persons from a friend who developed similar houses in Florida. There, his friend built 60 to 70 of this type dwelling in a complex called "Veterans Village."

Zaret thought that the need also existed in the Washington, DC, area for this kind of housing. He commented, "I expected to build about five or six a year."

Zaret planned routinely to include accessible houses in communities he developed, if he found a need existed. He did not intend to construct a special complex.

As it turns out, Zaret and his company have built only two houses which accommodate handicapped people since last year. The model home, which is located in St. Charles, Maryland, is still for sale. "Truthfully, I'm a little disappointed," Zaret explained. "I thought we'd get a better response."

The two houses which were built in the past year differ somewhat from each other. Each house has the basic model design, but then adaptions were made to accommodate the individual needs and wishes of the clients. One house, for example, has only hardwood floors because its owner uses a wheelchair, while the other has carpeting throughout the house.

The houses, which start at about $75,000, are being sold by Harrison Realty of Clinton, Maryland. A spokeswoman from the realty company, Gail Smith, stated that they received a considerable amount of responses to the model house and that most people who came to inquire about it were handicapped in some way. There were also inquiries from elderly people, as well as people who did not use wheelchairs.

Mr. Zaret noted that a group representing mentally retarded people was checking into getting a loan from the Department of Housing and Urban Development. They hoped to get funding so they could rent the house.

Zaret contacted the Veterans Administration to inform them about the house. He also listed the house with realtors in a multiple-listing service. "The article in the Post gave us a little publicity," Zaret said. "And we tried all the other avenues. But, we received only a few referrals."

Perhaps the reason is that the housing market is slowing down in general; or perhaps, even though the houses are reasonably priced, disabled people can't afford to buy them. Either way, Zaret can't find a market, and has no plans to build another accessible house in the near future.

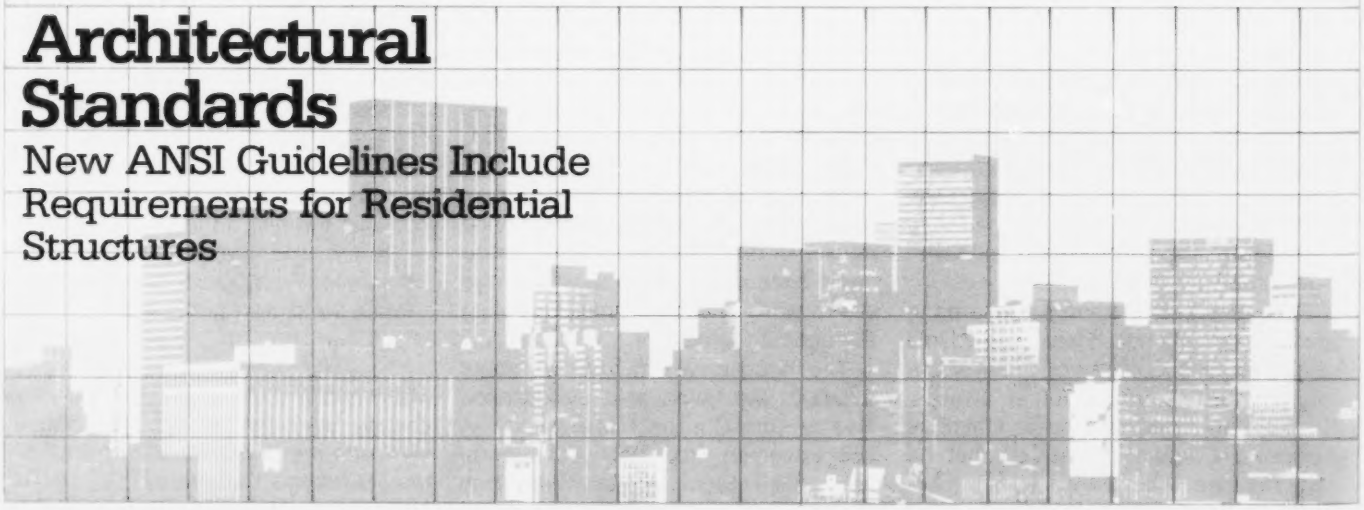
"But," said Zaret enthusiastically "if someone requested a house built —sure, we'd start right away!"

—Ellen Blanchard

Ms. Blanchard is a student at Galludet College who did her summer internship with the Communications staff of the President's Committee.

Architectural Standards

New ANSI Guidelines Include Requirements for Residential Structures



A new national standard containing specifications for making buildings and sites accessible to handicapped people is now available.

Known as ANSI A117.1-1980, the Standard was approved March 3, 1980, by the American National Standards Institute, a non-profit federation of trade, commerce, labor and consumer interests, which is the nationally recognized coordinator of voluntary standards development.

The project took five years of research and negotiations, involving a committee of 53 national organizations, which participated in the development work and balloted for the final consensus document.

It was led by a three-part secretariat composed of the President's Committee, the National Easter Seal Society, and the Department of Housing and Urban Development (HUD), with HUD assuming the funding and administrative responsibility.

The original American National Standard A117.1, approved in 1961 and reaffirmed in 1971, gradually grew obsolete as the years recorded wider recognition and acceptance of the place of handicapped persons in the environment.

It was originally intended to apply merely to public buildings. The specifications contained in the 1961 ANSI Standard were considered bare minimum. They reflected the degree of public acceptance and recognition of the needs of handicapped people at that time.

In the late 1970's the nation's design professionals called for more sophisticated and technical criteria to meet the problems of architectural and environmental barriers. The new ANSI Standard is the response to that call.

The Standard is divided into three major portions: General design principles, indoor accessibility for public buildings and residential structures, and outdoor accessibility. Outdoor accessibility covers such areas as curb ramps, recreational areas, and sidewalks.

The specifications summarize the extensive research done by the Syracuse University School of Architecture under the direction of Dr. Edward Steinfeld, who was the secretary of the ANSI project.

General design principles cover such areas as the installation of telephones and drinking fountains, wide doors and accessible stalls with grab bars in restrooms, and attention to the length of reach practicable for people who use wheelchairs.

Indoor accessibility covers such areas as emergency exits, which should be marked appropriately for blind persons, and visual information in warning systems so that deaf people can be warned.

Building entrances must be accessible, and located in primary areas, not back entrances, such as have been provided in the past.

Overall access must provide incorporation of design principles throughout the building, so that all persons have access. Segregated areas, for example, set aside for persons in wheelchairs, are not acceptable. And, sound systems must also provide for visual information for persons with hearing impairments.

The 1980 version of the ANSI standards is really an extensive revision and enlargement of the original standard, which has been referenced in federal and State laws, local codes, and anti-discrimination regulations relating to design for handicapped people.

It is expected that, because of its augumented guidelines, the 1980 Standard will have considerably more reference and application. For example, it is the first Standard to provide for housing in its provisions. It promotes the concept of adaptable design in residences, which allows for easy modification to accommodate handicapped residents when the need arises. And, it contains provisions for blind and deaf people which were not in the original Standard.

The new ANSI Standard has the goal of a single uniform standard of accessibility, essential in this day of overlapping laws, codes, and regulations at the federal, State and local levels.

To obtain a copy, Write: The President's Committee on Employment of the Handicapped, Washington, DC 20210.

—Edmond Leonard

Mr. Leonard is the director of Programs for the President's Committee.

The Cheshire Home:

One Example of New Housing Projects Being Built By Private Foundations

The Cheshire Home has offered sheltered housing to disabled people in other countries for many years. Now Cheshire Homes are being introduced in the United States. These Homes are representative of many such housing projects that are being built by private organizations in this country in an attempt to meet the needs of severely disabled people.

Sheltered, segregated housing is a controversial issue. But, it is, nevertheless, an alternative to institutional care which needs to be presented for further discussion. We invite reader reaction.

The prospect of living in a geriatric nursing home or in a State institution for the rest of one's life is hardly appealing. Nevertheless, it is frequently the fate of many disabled people.

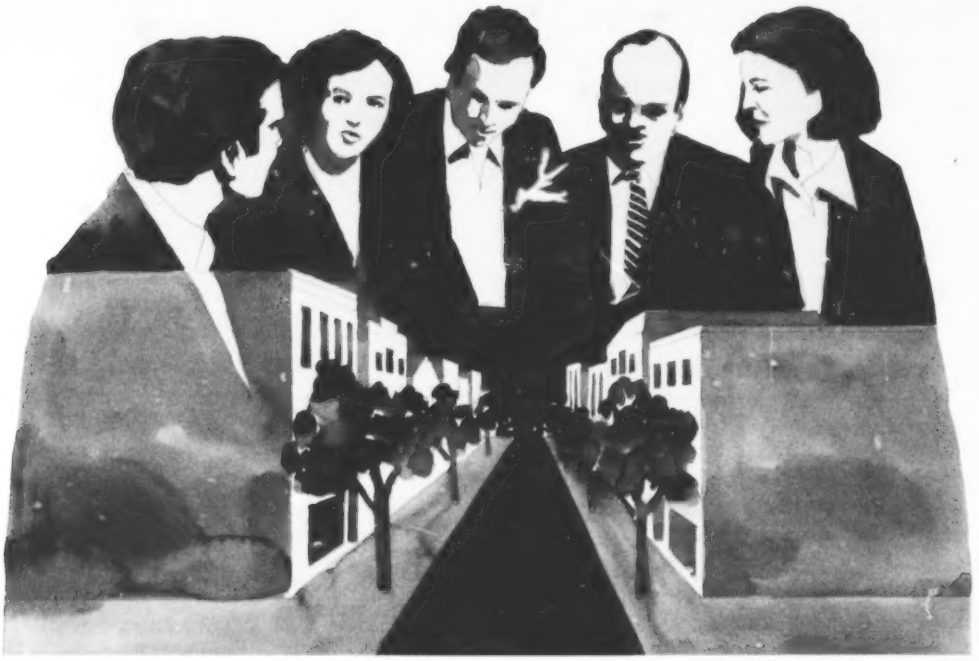
Some have been confined to institutions since birth. Others, sometime during their lives, have been institutionalized because their families could no longer attend to their specific needs at home.

Thousands of mentally alert young adults in this country who have been severely disabled as a result of an accident, birth defect, disease, or chronic illness, are, unfortunately, offered extremely limited choices in their living arrangements.

Nursing homes and State institutions care primarily for elderly persons and mentally impaired persons. But, at present, this kind of housing is disabled people's chief alternative for shelter.

This type of institutional living situation dramatically reduces the degree of independence disabled people may be able to achieve. It prevents them from enjoying the large scope of activities available to them. Accessible apartments are the answer for some, but not for those who need attendant care and do not have funding to pay for it.

Another alternative to this housing problem for severely disabled Americans is currently available in some areas of the country. According to the brochures, a Cheshire Home, as each one is termed, is a group residential home—not necessarily a permanent one—for disabled adults ranging in age from 18 to 50 years old.



At the Home, rehabilitation of the whole person is stressed, in hopes that she or he may be able to return to independent living in the outside community. For some who are more severely disabled, the Home is regarded as a lifelong residence.

The purpose of the Home is to provide an atmosphere in which residents are encouraged to develop their own skills and talents and to be as independent as possible. Emphasis is also placed on improving relationships among residents and on integration into the community.

The concept of a Cheshire Home may be new to the United States, but it certainly isn't new to the rest of the world. Currently, there are more than 180 Homes in at least 40 other countries.

Leonard Cheshire, a retired Royal Air Force bomber pilot, is responsible for originating this network of residencies. It all began in Great Britain after WWII.

Cheshire organized a plan for disabled veterans to work at various jobs. Because of their individual handicaps, many of them had to work together to complete one job. Unfortunately, this particular effort eventually failed.

Later, Cheshire heard that a 75-year-old ex-serviceman he knew was dying of cancer. The hospital where he had been admitted needed the bed for someone curable, leaving the man nowhere to go. Cheshire took the man into his own home and nursed him until he died.

Others in similar need followed and Cheshire accepted these people into his home as well. The new residents had a dislike for hospitals where they had received little attention and where they were regarded as useless. Cheshire realized this and assigned them each jobs to do which made them feel more at home.

Cheshire soon realized that the true need was in caring for young disabled people for which no specialized provisions had been made. He continued to start new Homes throughout England and each one was run by a committee composed of the Home's residents, as well as concerned local townspeople.

Today, each Cheshire Home throughout the world is completely independent and autonomous. The Homes are run by their own committees and function solely on the rules and decisions made by that individual committee. The Homes differ in size and type of accommodations, but they do share the same principles on which the first Cheshire Home was founded.

A Central Trust is established in each country, and this Foundation does offer some guidelines to the newly established Cheshire Homes which according to Leonard Cheshire, "they may or may not wish to follow."

The purpose of the Cheshire Foundation is to act merely as a guide for the Homes. The only financial support they provide, if necessary, is the initial stipend to get the new Home in operation. But some of the new Homes even refuse that monetary help.

"In Africa recently, a new Home was started, but the residents turned down our help. They wanted to make it on their own," Cheshire stated. The Homes depend mostly on private contributions for daily operations. The government does not offer any subsidized funding.

One of the major resources for the Cheshire Homes is support from the

local community members. The active participation of community people has added immensely to the success of the housing network. According to Michael Teague, Chairman of the Board of Directors of the Cheshire Foundation, the local community plays an important role in the Homes' future.

"We try to involve the townspeople right from the start," Teague reported. "We inform them and discuss our plans and let them know what Cheshire Homes are all about. By including the neighboring community into the plan for the development of the Home, a good rapport is generated from the beginning."

Another reason cited as to why the community tends to support these Homes is because they are kept "small." They are not institutions and have no intentions of becoming grand scale operations. "Small is beautiful. It works!" Teague announced with a smile.

All applicants to the Homes are considered without regard to sex, race, creed, financial or ethnic background. When a new Home opens, the Cheshire Board of Trustees selects residents who are representative of the local community. In an already established Home, new members are chosen by an admissions committee composed of other residents and a few members of the local Board.

Residents who hold jobs pay what they can for their room and board. Others rely on insurance such as Medicaid, Social Security, and VA benefits to cover the living costs.

Attendant care is an additional costly burden to disabled residents in the United States and to disabled people in most other countries. Medical insurance, again, is relied upon to cover these costs. In Canada, however, and some other countries, national health policies cover these costs.

In the States, Cheshire Homes are beginning to spring up all over. In California, there are presently three Homes, one of which is run strictly on a rented room basis. (Because of lack of funds, each resident must pay for room and board.)

In Mississippi, another Home has been established which differs from the rest in that it accepts mentally retarded residents as well as physically disabled ones. The Nevada Self Help Group is also in the process of beginning a Home in Reno.

"The most ambitious scheme of all," Michael Teague explained, "is the undertaking in New Jersey." Recently, ground-breaking ceremonies took place to launch the building of a new Cheshire Home which, when finished, will accommodate 35 disabled people.

The Home has a barrier-free design and will be one of the largest of the Cheshire Homes in the world. The land for the housing complex was donated by the Exxon Corporation, and the money for the Home's construction was raised by a federal loan and through private contributions.

The 1.8 million dollar home is expected to be completed in about a year. The Home will consist of single and double rooms, each being large enough to be personalized and to accommodate "work space." Also, each room will open onto a patio.

Dining and recreational rooms are located in the central part of the building, as are hobby rooms, a library, TV lounges, a personal care center, and a "sundry shop." In addition to the main dining room, there are kitchenettes and den areas so that residents may entertain guests.

One of the main problems that this Cheshire Home will face, as do many of the others throughout the world, is the selection of its residents. Presently, there are well over 100 applicants on file at the Home in New Jersey. Undoubtedly, many more will apply by its expected opening next August.

A similar facility, the Good Shepherd Home in Allentown, Pennsylvania, currently has a five-year waiting list. The only encouraging factor is that many of the applications were submitted over a year ago when the plans for the Home were still in the making. Some of those applications may not be valid today.

The founder of the Homes, Leonard Cheshire, in speaking at the ground-breaking ceremonies in New Jersey, may have described the Homes most accurately. Cheshire stated that "the idea of the Homes is not to create an atmosphere of independence, but rather to provide a freedom of choice for disabled people in where they can live."

Inquiries about the Cheshire Home in New Jersey may be addressed to Dr. David M. Graybeal, Chairman, Cheshire Home, Inc., 1 Madison Avenue, Madison, NJ 07940. For information about other Cheshire Homes in the United States, write to The Leonard Cheshire Foundation, Inc., 12211 Connecticut Avenue, N.W., Washington, DC 20036.

—Ellen Blanchard

Ms. Blanchard, a summer intern from Gallaudet College, worked in the President's Committee's Communication office.

In looking at housing options for disabled people, we have looked at some specific ideas and accommodations. But, whether we are discussing adapting housing or transportation or education, what we are really talking about is being accommodating in our attitudes. This story suggests how we can do that.

Accommodation: Putting Words Into Action

Be it on an airplane, in church, at the stadium or symphony hall, my tall father had to ask for an aisle seat to accommodate his long legs. He needed an extra length bed. And, as the only man in the house, he opened all the "easy twist-off" jars my mother, my sisters, and I couldn't budge.

Blessed with my father's height, I'm handy for reaching high cabinets and the tops of dusty closets. I share an office suite with a woman who is five feet tall. When we requested the maintenance staff to position a wall hanging at eye level, they wisely asked: "Whose?"

Everyone is better at some things than at others. Most of us work at jobs that require our particular talent and training. We drive cars that suit our physique and our lifestyle, and we adjust the seats for our passengers. We sit on furniture that fits us.

In the daylight we wear sunglasses, at night we read by proper lighting. We shop in clothing stores that carry our size. We stack our kitchen shelves according to the range of our physical reach, and we develop relationships with others according to the range of our emotional reach.

In other words, we adapt our environment to our abilities, and create a world in which we can live comfortably.

To many people, a disabled individual is someone born with something physically wrong, like cerebral palsy or blindness, symbolized by the gum machine picture of a child in leg braces, or the official wheelchair logo of the handicapped.

A disabled individual is someone who lost a physical ability he or she once had, through illness, accident, or military combat. In reality, handicapping conditions include alcoholism, cancer, diabetes, epilepsy, drug addic-

tion, heart disease, mental retardation, and other disabilities less obvious than the usual understanding of the word.

The fact is, we were all born with handicaps of one kind or another, and we were all born with gifts. We acquire disabilities and skills as the years pass. We are human beings with talents, and with limitations. Some of us can't open a jar, others can't bear loud noises. Some of us are math whizzes, others can't spell. We suffer from phobias. We have allergies. We wear glasses, contact lenses, hearing aids, and pacemakers.

The language surrounding people with disabilities has proliferated with recent efforts to improve the quality of life. It is a language which includes medical terms like dyslexia, aphasia, cardiovascular accidents, myocardial infarctions, and multiple sclerosis; and abbreviations like CP, CVA, MI, MS.

Legislation has given new meaning to words like accessibility, eligibility, reasonable accommodation, affirmative action, mainstreaming. Numbers, acronyms, and abbreviations operate as words: 503, 504, PI 94-142, DVR, ACCD, EEO, PCEH.

The word "accessibility" too often suggests architectural pillage, like the intrusion of a ramp upon the aesthetics of a gracious Gothic building with a marble staircase. It is a word which seemingly threatens thousands of dollars for transbuses with hydraulic lifts that only a few people will ever use. It means radically renovating bathrooms, and hanging signs at navel level. It means empty handicapped parking spaces in a full lot.

Yet accessibility can be as simple as the laying of a board over your back stoop so an acquaintance in a wheelchair can visit your home, or offering an arm to someone having difficulty crossing the street. It can be as makeshift as altering the door of a bathroom stall with a piece of string, so that it swings out instead of in.

The words "adaptive equipment" awaken images of elaborate electric wheelchairs, automobile hand controls, and expensive audio-visual aids. Yet we use adaptive equipment everyday.

We bring mats for those hard bleacher seats at a baseball game. We put phone books on chairs for our children. We use binoculars. Adaptive equipment can be as simple as clay around the handles of utensils for someone with arthritis. The best adaptive equipment is sensitivity.

And "mainstreaming," perhaps the most important word, commissions us to enrich our lives with people whose experience is different from ours. Mainstreaming means including people with disabilities in the professional, social and recreational flow of our lives. It challenges each of us to contribute what talents we have to the human family, and offset our own limitations with another person's gifts.

—Christine Cleary

Ms. Cleary is publications editor for the Curative Rehabilitation Center, Wauwatosa, Wisconsin.

Housing: Read All About It

The following publications contain information of interest to people with disabilities.

A variety of needs must be met in order for disabled people to truly benefit from new housing programs. They need to know what services are available and what technology can assist them in living independently. Disabled people also need information on the housing choices available to them.

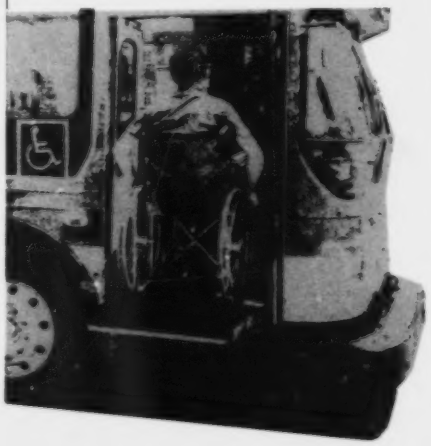
The following is a listing of some of the publications and services available to disabled people. It includes information for those who would like to improve their housing situation and for those who are considering the possibility of independent living.

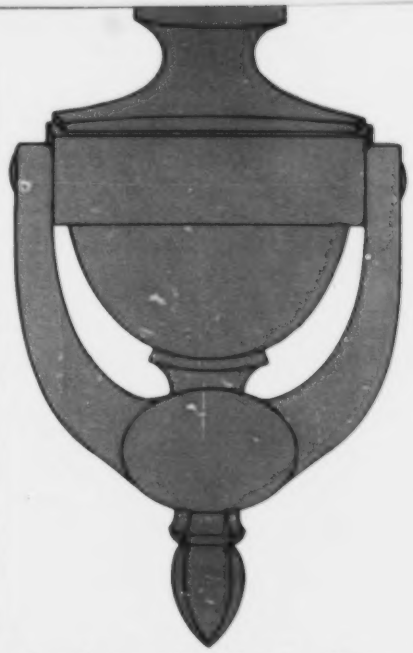
Mobile Homes . . . "Mobile Homes: Alternative Housing for the Handicapped," is a booklet developed by St. Andrews Presbyterian College and the Department of Housing and Urban Development. It is a comprehensive study of how mobil homes can be made accessible to handicapped people. It covers kitchens, bathrooms, safety, site considerations, and other features. It gives specifications for space and building, and analyzes the food flow in the kitchen, and where appliances can be located for best use.

"Mobile Homes" has a common sense approach that is easily understood and followed by the layman.

"Mobile Homes: Alternative Housing for the Handicapped," is for sale by the Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402. Stock Number: 023-00393-7.

Access Guides . . . "International Directory of Access Guides," is a 24-page directory published by Rehabilitation International, USA. It lists nearly 350 publications. These publications give information about accessible buildings and transportation in cities throughout this country and the world. Single copies of the publication are available from Rehabilitation International, USA, 20 West 40th Street, New York, NY 10018.





Low Income Housing Services . . . The National Handicap Housing Institute (NHHI), is a private, non-profit organization which specializes in accessible housing which meets the independent living needs of disabled people with low incomes.

Services provided by the NHHI include research on design standards for housing, information and referral, design counseling, and Sections 503 and 504 compliance. It also has information on surveying for accessibility, and information on housing marketing and management.

The NHHI has also developed publications on the housing preferences of people with disabilities, and on available hardware, equipment, and appliances.

For more information, write the National Handicap Housing Institute, 12 South Sixth Street, Minneapolis, MN 55402.

Student Housing . . . "The Disabled Student on American Campuses" is a book summarizing five days of presentations, work group discussions, and conference recommendations of a national conference held at Wright State University in 1977. In addition to the presentations on accessibility, the book contains summaries of the work sessions on planning, services, evaluation, finance, law, and research.

Copies are available at no cost from: The Office of Handicapped Student Services, Wright State University, Dayton, OH 45435.

Independent Living . . . "Design for Independent Living: The Environment and Physically Disabled People," is a thoughtful look at the environmental barriers disabled people face.

Written by Raymond Lifchez and Barbara Winslow, the book presents in-depth profiles of seven disabled people who live in Berkeley, California. It illustrates their formal and informal support systems, and gives a series of design solutions to the problems these people face.

About a fourth of the book contains a catalog of designs, adaptations, and tools, which provide practical and creative solutions to a large range of design problems.

To order, write: Whitney Library of Design, 1515 Broadway, New York, NY 10026. Cost: $25.00.

Catalogue . . . A catalogue developed by the Michigan Center for a Barrier Free Environment, in collaboration with consulting architect Robert Williams, lists products which can be used as equipment in creating barrier-free design facilities. The catalogue includes the names and addresses of nearly 300 manufacturers.

"Barrier Free Design Equipment and Aids Catalogue" is cross-referenced with 112 product categories. These provide an easily-used source of information for consumers and professionals interested in barrier-free design aids and equipment.

To obtain a copy, write: Michigan Center for a Barrier Free Environment, 6879 Heather Heath, West Bloomfield, MI 48033. Cost: $5.00, plus $1.00 for postage.

Guides on Housing . . . Two publications on housing for persons with disabilities are available from the National Association of Housing and Redevelopment Officials (NAHRO).

"Housing Handicapped and Disabled Persons: A Training Manual," was written by Joanne Hogue. The 144-page book is in loose-leaf form. It has materials, instructions, and information on training trainers. These trainers can then help interested groups who want to plan and develop housing for people with disabilities.

"Housing for the Handicapped and Disabled: A Guide for Local Action," by Marie Thompson, is a resource guidebook for communities. The guide discusses how to expand housing activities to serve people with disabilities. The book has a step-by-step treatment of each part of the housing and development process, and offers basic information local groups can use.

For more information about both of these books, write: Judy Morris, National Association of Housing and Redevelopment Officials, 2600 Virginia Avenue, Suite 404, Washington, DC 20037.

Home Accessibility . . . "The Source Book For the Disabled: An Illustrated Guide to Easier, More Independent Living for Physically Disabled People, Their Families and Friends," assists disabled people who want an independent lifestyle.

While also covering many other areas, the book goes into considerable detail in describing adaptations which can be used to make the disabled person's home accessible.

It discusses alternative placement for furniture, outlets, stairs, floors, doors, and entryways. It also includes kitchen and bathroom plans.

The "Source Book" is available from Paddington Press, 95 Madison Avenue, New York, NY 10016. Cost: $4.95 paperback, and $15.95 hardcover. Include 75¢ to cover postage.

Buyers' Guide . . . "Accent on Living" magazine has published a list of products for use by disabled people. "Buyers' Guide" is a 96-page booklet which lists hundreds of items, and is indexed for easy cross-reference. Areas covered include housing and architectural barriers. Under each general category, specific types of products are indicated, along with a listing of product manufacturers.

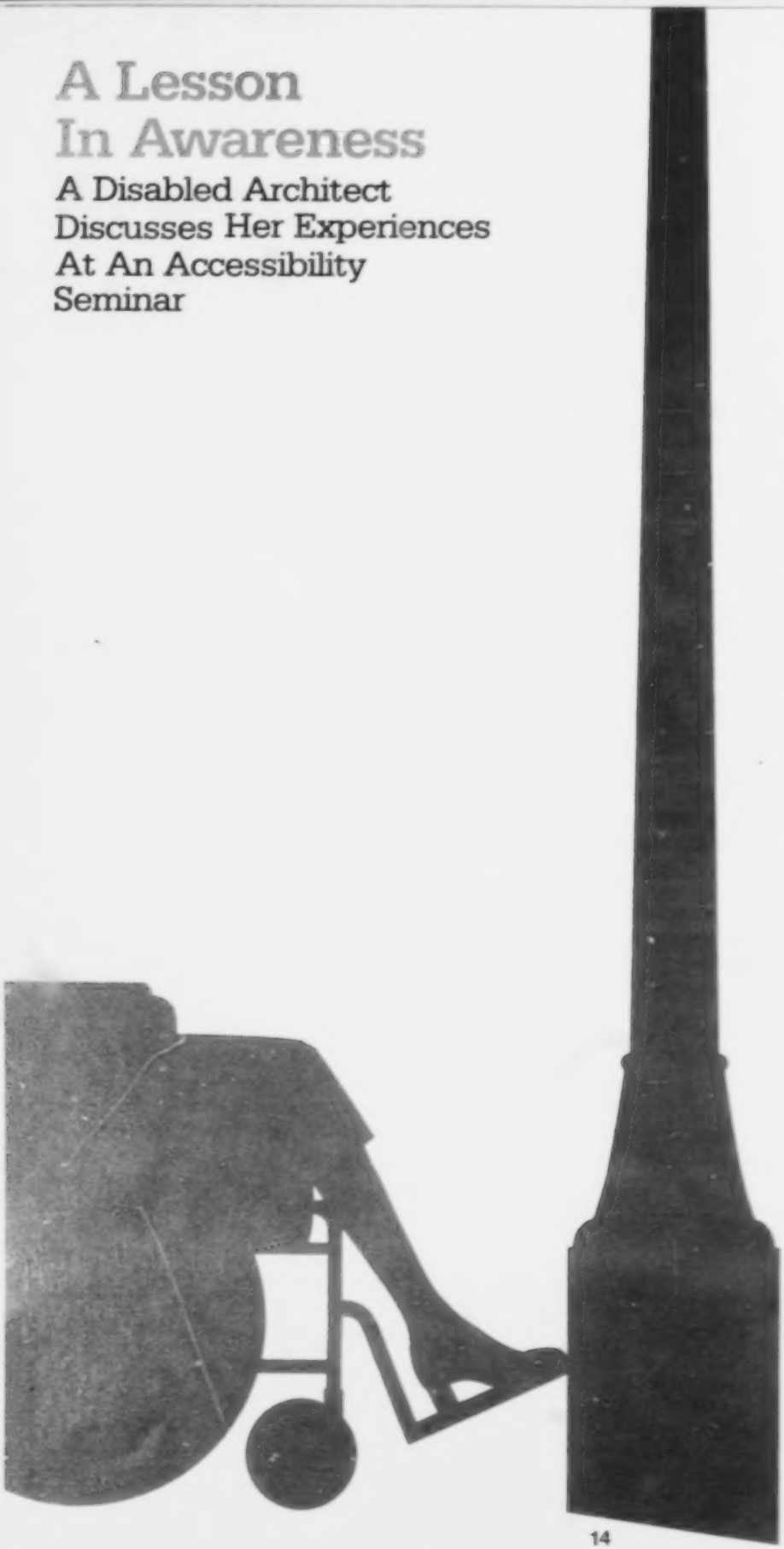
To obtain a copy, write: Accent on Living, P.O. Box 700, Bloomington, IL 61701. Cost: $10.00, plus 55¢ postage.

—Muriel Strassler

Ms. Strassler is a past staff member of the President's Committee's Communications office.

A Lesson In Awareness

A Disabled Architect Discusses Her Experiences At An Accessibility Seminar



In this issue, looking at housing opportunities for disabled people, it is important to remember the part architects and planners play in making the environment usable by disabled people. In order for the disabled person to function in any housing the surroundings must be accessible.

The following experiences of a disabled architect shed some light on the attitudes that may cause problems for disabled people who are being assimilated into the community.

I had come to Cambridge, Massachusetts, for a seminar offered jointly by Harvard's Graduate School of Design and MIT's School of Architecture and Planning. The seminar was part of their continuing education program for professionals. Titled, "Accessibility and Barrier-Free Design," the course was specifically directed towards planners, designers, and representatives of public and private institutions and agencies concerned with compliance of federal law requirements.

As a practicing architect who is disabled, my initial intent when I enrolled in the program was to increase my storehouse of information about design for accessibility. After all, accessibility should be basic to all good design.

I also considered myself, as an architect, more sensitive to these issues than most. I was soon to discover that I had much to learn about myself and my surroundings.

As part of the seminar we were asked to take part in a sensitivity workshop session. All participants were to role-play a variety of handicaps while exploring portions of historic

Cambridge. I decided ahead of time to choose the wheelchair, thinking, falsely, as it turned out, that my past experience would give me an advantage. I also hoped I would avoid exhaustion, because walking long distances is difficult for me.

On the second day, each group member selected a specific disability which was to be assumed while we made our way through a diabolically plotted series of assigned tasks.

These included: "Find the wheelchair route into the Pusey Library." (This particular task turned into an overwhelming problem I was never able to solve). My encounter with the Harvard Square Newsstand (I was supposed to browse inside) became an exhaustive exercise in coping.

The experience generated many feelings in me. I struggled outwardly with a variety of "aesthetic" new and/or unrepaired "historic" paving materials, cross-grades, strange curb ramps, or, lack of them. There were utility poles strategically placed in the middle of curb ramps, and thresholds, door swings, carpet textures (the list seems endless). Inwardly, I became aware of a subtle sense of loss.

I found my attention directed downward by necessity to the immediate terrain I was attempting to negotiate. I couldn't allow myself the luxury of enjoying urban spaces and people.

In effect, I became deprived of the opportunity to be a part of the environment around me. The quantity of the obstacles kept me from enjoying the quality of the historic surroundings.

I had always thought I was able to handle such problems with a sense of humor. Now, I begin to feel vaguely frustrated and alienated. I was becoming self-absorbed with the task of reaching physical goals. The quality of the trip no longer mattered; what was important was just getting there. Priorities began to shift by necessity.

By the end of the day I was filled with anger. I was angry at anything and anyone that stood in my path of travel, and that anger was exhausting. Spontaneity became almost impossible: the feeling of choice eroded.

As the inaccessible environment forced me to become more dependent upon others for help, I began to feel like an infant. Often, people became overly helpful, or, when asked questions, would direct their response to the most able-bodied of our "group."

Soon, I began to respond to my role. By learning to display "helplessness," I quickly discovered I could get the assistance I needed. However, the price paid was dear. I found myself often being treated as a person with the maturity level of a small child.

The concept of needing one's own personal territory became another hidden barrier I had not been aware of before. As I found myself attempting to function in a crowded environment, I soon discovered the increase in space required by the wheelchair. I was dependent upon a mechanical device for mobility. Using this device encroached upon people around me.

It is important to remember that the term, "mechanical device," encompasses walking canes used by the blind, walkers, and crutches, as well as wheelchairs. For those like myself who have ambulatory difficulties, which involve an unnatural gait and lack of balance, more territory is required in order to feel "safe."

While adapting to my role in a wheelchair, I became aware of behavior that was out of character for me as a person who walks. In an effort to compensate for my diminished stature, I began to be overly assertive.

Being in the wheelchair evoked condescension from those walking. I quickly learned I could behave in a childlike, brattish manner that would not be tolerated if I was walking.

Nevertheless, I encountered more hostility as population density increased. This feeling was particularly notable around subway accessways and areas subject to heavy pedestrian traffic.

All of us, as consumers, have the right to demand aesthetic and technical expertise from our architects and planners. We should also expect an understanding of the social benefits of accessibility and a willingness to include these benefits as goals for every design project.

Environments should be created that are accessible to all users to the greatest degree possible. Accessibility is not a negotiable requirement. What will then follow naturally will be an environment in which all people can function in a natural and spontaneous way.

I thought, as a disabled architect, I had an awareness of consumer needs. The seminar taught me I had much more to learn.

—Carolyn Mano

Ms. Mano is a disabled architect in Arlington, Virginia.

Independent Living:

Housing Opportunities for Persons Who Are Both Mentally and Physically Disabled

I've been here five months and I like it very much," said Joseph Rucuzzo. "I'm out on my own. I'm as independent as I can be."

He speaks in a living room with a large picture window. It is furnished nicely, with brown wall-to-wall carpeting, a brown couch, chairs, a table, and a color TV. Located in East Boston, the four-room apartment meets Rocuzzo's needs.

He is a large man, with a thick beard. His hair is black with streaks of grey. He sits in a wheelchair, due to cerebral palsy.

He also has another handicap—mild mental retardation. He was a former client of the Wrentham State School, a large institution for retarded citizens, administered by the Massachusetts Department of Mental Health. Now he is part of a pioneer project, the first independent living program in the country for citizens who are both physically disabled and mentally retarded.

This project was initiated by the Boston Center for Independent Living (BCIL). Founded in 1974, BCIL is the first independent living program on the East Coast. Over 50 percent of the members of their Board of Directors are consumers.

The project has three basic levels of independent living:

The transitional living program teaches residents how to live on their own. They live in an apartment, and learn basic skills such as how to supervise attendants, how to budget, and how to deal with a landlord. The residents also learn how to shop for themselves.

The cluster living program is designed for group living. Several people live in adjoining apartments and share attendant care, transportation, and other resources.

The independent living program allows clients to live on their own and supervise their own personal care attendants. However, BCIL provides services when they are needed.

BCIL negotiates the necessary red tape with Medicaid so that clients can pay the wages of their attendants. They have a pool of personal care attendants in case of emergency, and they provide professional help in adapting apartments. In addition, when necessary BCIL acts as a legal advocate.

The progam is designed for former residents of rehabilitation hospitals, nursing homes, and State residential schools. People are taught how to be responsible for their own health. They also learn to supervise their personal care attendants.

The personal care attendant helps with any daily needs of the client such as dressing, cooking, and bathing. They are hired, fired, and paid by the resident. The personal care attendant program grew out of a strong belief that the client should take control of his or her own life.

According to Dr. Paul Corcoran, Chief of Rehabilitation Medicine at Tufts-New England Medical Center and one of the founders of BCIL, "If you're a patient and the nurse is giving you a bath, you follow the nurse's instructions. But if your personal care attendant is giving you a bath, your instructions are followed."

The Boston Center for Independent Living now has 126 people living independently. Their transitional living program has 11 people. BCIL also has another grant to provide protection and advocacy services to disabled people in the community.

The pioneer project for people who are both physically disabled and mentally retarded has five clients. Four have cerebral palsy and one has spina bifida. Most of them have spent more than three decades in institutions.

According to Kathy Fyfe, who supervises the program, the clients are thoroughly evaluated prior to entering the project. The staff learns the clients' reading level and problem solving ability. Comprehension and the ability to handle a crisis is also measured.

From this the staff writes a detailed individual service plan, which includes specific goals for the client.

Fyfe stated, "We provide clients with 24-hour staff coverage. The personal care attendants work with them on dressing, bathing, and personal needs.

"Skill instructors teach them to manage the personal care attendants, to advocate for themselves, and to develop other self-help skills such as landlord-tenant management. They also help the clients discover what they can do independently with their disability.

"Because they have had to live so long in an institution, they have to learn to live in the community. Their responsibilities in the community are greater than they have had before.

"They are responsible for keeping their apartments clean, paying rent and phone bills, organizing their own recreational activities, setting up transportation, and making medical appointments. The residents of this program

are motivated and willing to learn."

Most clients are pleased at the opportunity to have more freedom and leave the institution.

"Wrentham State School was lousy," said Joseph Roccuzzo. "You had to ask the staff if you could go outside. They'd take me to the bathroom. They'd tell me to wait and I had to wait. The meals were always cold. I never used to eat. I'd go to the canteen and buy food."

Johanna Goode, a woman with cerebral palsy who is in the program, stated, "They were mean. Everybody was mean. No one paid any attention to me."

Both Goode and Roccuzzo had moments of sadness at leaving the State school, however. Goode explained, "I miss the school. I had a boyfriend at Wrentham. I can visit him, but it's not the same as being with him."

Roccuzzo said, "There are times when I feel I want to go back to the Wrentham State School. But, I don't really want to go back. I like it here. I can tell people what I want.

"I'm learning how to get along with people. I'm learning how to budget. You put it in the bank. I go to school right now. It's called the therapuetic community.

"I type, I'm learning how to read. I want to learn how to read."

Bob Williams, Director of Boston Center for Independent Living, described a woman who had been diagnosed as retarded, but who was ready for their regular transitional living program.

"Initially there were some problems. She had a tough time breaking away from the institution. All of her friends were there. She would get morose. But she got into some really good day activities.

"She's been there eight or nine months. Now she's bugging me to help her move into one of the apartments. She has a roomate. She's ready to go."

Williams described the history of the program. "I was on a panel on housing at a conference held by the Boston Self-Help Center in September of 1978. After a few minutes of panel discussion, five or seven disabled prople from Wrentham State School began to ask questions. They were asking basic questions like, 'When are we moving out?' 'Is there housing for us?'

"Well, of course," Williams continued, "I took all of this very seriously. I started to make calls to the Department of Mental Health. They admitted they had put the program together very quickly. They were under court order to deinstitutionalize.

"And then the Department of Mental Health began to ask us about what BCIL did. We told them, and we both began to think about a contract.

"We decided to use our own transitional program. We played around with our model for two or three months until we came up with what we thought made sense for this population.

"We intensified our staff coverage. We developed an active recreational and social program for weekends and evenings.

"The Department of Mental Health has its clients go to day activity programs such as prevocational workshops and schools. So we had to work our system around the fact that the clients were gone from 8:00 to 4:30.

"The residents have been diagnosed as mentally retarded. Whether they were mentally retarded or not, it seemed to us that after 25 years, they certainly would be institutionally retarded."

Williams and his staff met with staff people who had worked in the Wrentham State school. The clients were evaluated by a nurse and occupational therapist.

A few residents moved right into the transitional living program. Some people were so long neglected due to their physical disability that they seemed mentally retarded; but, in fact, their degree of retardation was not that serious.

By July of 1979, BCIL had a contract with the Department of Mental Health. And by September of that same year four people had been evaluated, interviewed, and accepted.

"The people at the Department of Mental Health were very cooperative," explained Williams. "They made every effort to make this work."

And the results of all this work by dedicated administrators and public servants? How do the clients themselves feel?

Johanna Goode explains, "I didn't like it before, but now I do. I'm learning to shop for food.

"Someone's teaching me about money, about how twenty-five cents is a quarter and ten cents is a dime. I like to learn about money. I like to learn to shop. I like it here and I don't want to go anywhere else."

Joseph Roccuzzo is thinking about his future. "I'd like to be a foreman, tell people how to put nuts and bolts together. I'd like a job like that. I could handle a job like that."

—Dale Brown

Ms. Brown is on the Communications staff of the President's Committee.

Curtis Brewer: Handicapped American of the Year—A Bold Innovator

"Be bold, be bold, and everywhere be bold."

—Edmund Spencer

An apt description of Curtis Brewer, a man of action, who sometimes uses unorthodox methods to get things done.

For example: He had an important message for those who would attend the opening session of the President's Committee's Annual Meeting. At the last minute he was told he couldn't give it.

President Carter had decided to attend and there would be no time for Brewer's message. Brewer refused to accept this decision.

Curtis Brewer, the 1979 Handicapped American of the Year, was to receive the President's Trophy from the President. But, he would pass up this honor if it meant he could not present his views—he felt his message was important, also.

And the decision was reversed. Brewer was given time to speak.

The Handicapped American's message was, in essence, that "equality in all aspects of daily life and work is a right of handicapped people," that disabled people should be in all departments of the government "not because we're handicapped, but because we're capable," and that "disabled people will achieve ranks through laws."

Another example. Curtis went on a VIP tour of the White House. He went from the first to the second floor in an elevator provided for tourists with mobility problems. His wheelchair barely fit into the elevator, and he was discharged in a utility area of the White House.

He insisted that he be returned another way. His request was granted.

The guide brought him down on the President's elevator.

"If we would guide by the light of reason, we must let our minds be bold."

—Louis D. Brandeis

Brewer, now 55 years old, has had to let his mind do everything for him. For almost 25 years he has been completely paralyzed from the neck down by transverse myelitis, a spinal cord inflammation. He must use an electric wheelchair for mobility. Yet, when he talks to you, you feel as if he is waving his hands or walking about to emphasize a point.

He must also depend on others to care for him. But, he depends on *no one* to do his thinking. In fact, some say he thinks 24 hours a day. Because using a portable respirator makes it hard for him to sleep, he often calls his family or one of his four attendants in the middle of the night to record an idea or project, to take a letter, or to just give him a cigarette.

His work allows him to utilize his brain fully. He is an attorney in New York City and a member of the American Bar Association.

An imposing man with penetrating eyes, he entered Brooklyn Law School in 1970 to prepare himself to meet the need for legal advocacy services, and to help the legal profession understand the desires of disabled people. In 1974, he received his Juris Doctor Degree.

According to Brewer, the potential of disabled people has virtually been unheeded in the past and, to some degree, still is. Through Untapped Resources, Inc., the non-profit organization he founded in 1964, and still directs, he provides free, legal aid to disabled people. He helps those who don't know where to go: those who are having trouble with the law and those who need services of public institutions.

He feels that disabled people should not be a "so-called invisible minority of untapped human resources" in America. His home in his office—crowded, yet well organized and efficiently run. Presently his staff consists of three attorneys, a paralegal, an ad-

ministrative trainee, four attendants, a bookkeeper and Mrs. Venable, his "gem of a housekeeper and factotum.

Originally, Untapped Resources provided ombudsman-type social services to "research and study social and economic conditions" as they related to disabled people. Now it "represents undertaken in the last four years.

Most of the time Brewer uses the language of a well-educated man. But when he discusses barriers that hinder his movement, and therefore his work, he sometimes slips into the language of the street. In fact, he refuses to enter inaccessible buildings.

"Be bloody, bold and resolute."

—Shakespeare

individuals with gut-related problems of survival."

Untapped Resources arose out of Brewer's struggle to survive. "By improving the lot of disabled people as a whole, I improve my own lot." As my mother said, 'Charity begins at home and spreads abroad'."

He was vehement in saying that a barrier-free environment is the "cornerstone to disabled people." He feels access is necessary to change attitudes in what is essentially a hostile society. One day he hopes to argue this point before the U.S. Supreme Court. A top priority for him in the

A thorough man with a penchant for details, Brewer once went to the National Multiple Sclerosis Society without an appointment to find out how multiple sclerosis affects individuals medically. He wanted to help a client who had been denied Social Security benefits.

The Social Security Administration had ruled that multiple sclerosis was not a physical impairment, but a mental one. As a result of this case, the Administration reversed its decision.

Jack Wood, the man Brewer visited at the Multiple Sclerosis Society, described Brewer as a charismatic and formidable man who looks for precedent setting cases. "If he wins, thousands of disabled people will benefit."

Brewer's philosophy is to try "to win for disabled people what is already on the books." And win he does. He has won 435 of the 450 cases he has

1980's is to continue to work toward "crumbling" attitudinal and architectural barriers.

Curtis has been honored many times for his work. But, how did he feel about being selected Handicapped American of the Year?

"It's a dubious honor, unless my becoming the Handicapped American can somehow enhance the struggle of disabled people to have greater self

people and the people who support them."

The passing years sometimes slow some of us down. Not Brewer. In 1978 he expanded the operation of Untapped Resources by launching a radio series, "Law and the Disabled," a biweekly New York City program, over In-Touch Networks, WKCR-FM and WFUV-FM.

The series, which he hosts, presents legal cases of people deprived of their rights. In addition to presenting the individual's case, Brewer presents the views of the agencies involved, and commentaries from experts in the disability fields. The series has been well received by the public.

This spring Curtis began a new effort to set up "reciprocal relationships" among disabled people, business, and government agencies. "The aim is to enable disabled individuals to enter, reenter, or remain in industry, while actually reducing corporate tax and insurance costs."

In addition, Brewer said, the plan, called GUTS (Greater Utilization of Tools and Services), "is intended to challenge disabled individuals to help themselves and society by becoming involved in their own destiny."

He continues to be active in organizations such as the American Coalition of Citizens with Disabilities and the National Rehabilitation Association. He gives lectures, participates in seminars, and is frequently a guest on radio and television programs.

Curtis Brewer was selected as Handicapped American of the Year because of his accomplishments. It is clear that he has done a great deal to open doors for disabled people. It is also clear that Brewer does not feel he can sit back and rest on his laurels.

"Look with favor upon a bold beginning."

—Virgil

esteem, to be recognized as human beings, and to further the work of the President's Committee and my organization."

What is important, he emphasized, is that the award should not put one disabled person on a pedestal. "It should be representative of all disabled

Brewer is not nearing the end of his work. In fact, for him, the work has hardly begun.

—Juanita Campbell

Ms. Campbell is on the Communications staff of the President's Committee.

New Law Eliminates Some Work Disincentives

This story is the first of a two-part series on recent legislative changes in the federal disability benefit programs. This article discusses the legislation in general and explains some specific changes affecting persons who receive Disability Insurance.

Employers willing to hire and promote qualified handicapped persons complain that there are no disabled applicants for jobs. Sadly, this is all to often a valid complaint.

Many disabled people have chosen to stay at home or take low-paying, part-time, intermittent work. It is not because they don't want better job opportunities. Rather, government regulations have forced otherwise capable people to be nonproductive.

Many disabled persons who are recipients of disability benefit programs have had to avoid employment. Because they are physically or mentally impaired and without a significant work history, unless they can enter the work force at a high income level, they have avoided any sort of participation.

According to Social Security regulations, a few months of work activity, even at relatively minor amounts of earnings, rendered a recipient no longer disabled in the eyes of the law. When this occurred, the disabled person lost all eligibility for cash assistance from Disability Insurance (DI) and Supplemental Security Income (SSI) programs.

Moreover, he or she lost eligibility for other programs that are "linked" to an active status with DI and SSI. These other benefit programs include Medicare, Medicaid, and Title XX social services, such as attendant care and home management counseling. Because of the regulations, it seemed too risky to take full-time work—loss of financial and health benefits could be devastating.

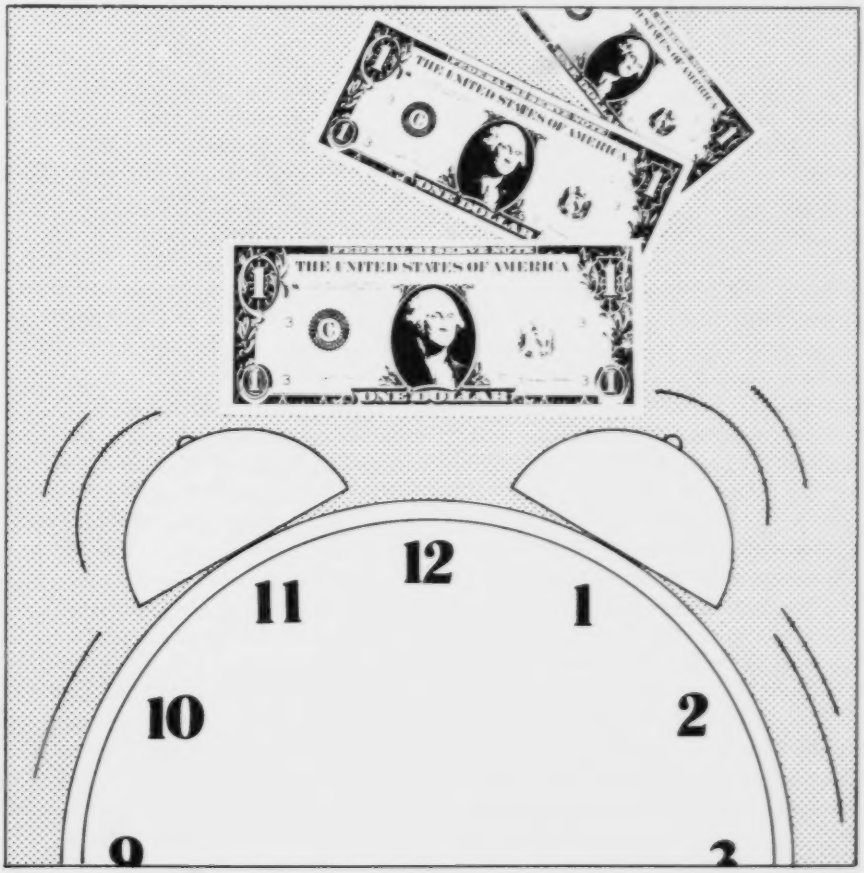
Even more tragically, disabled persons sometimes have not fully comprehended the Social Security regulations on earned income. In attempting work, they unknowingly set a clock ticking that soon left them without needed financial and life-support resources.

Two years ago in Los Angeles, a young disabled woman committed suicide when her part-time employment suddenly left her without her SSI assistance, Medicaid coverage, and attendant care. Doubtless, other disabled persons have stumbled into the same predicament, but this woman was the first to leave a recording on which she cited the Social Security action as "the straw that broke the camel's back."

For years, this young woman and other disabled persons advocated basic changes in how the law regards disability. They wanted to work. But, they were always facing an all-or-nothing situation.

You qualified as disabled because you were impaired, poor, and inactive. Then you received full benefits. It was not possible to be impaired and receive *some* benefits to supplement your earnings; if you were not qualified to receive *full* benefits, Social Security would not allow you *any* benefits.

Legislation recently passed by Congress and signed by the President does much to alleviate this all-or-nothing situation. It greatly reduces the finan-



cial and health risks for disabled recipients of federal assistance who attempt employment. The legislation is PL 96-265, entitled "Social Security Disability Amendments of 1980."

PL 96-265 is a large package of legislation that will affect many federal welfare programs by 1981. Regarding disabled persons interested in working, under the new law, some or all cash, medical, and social service benefits will continue for a longer period after work begins. Currently, these benefits are available for only a short period of time.

In the disincentive provisions of PL 96-265, Congress for the first time in law is recognizing important facts about disability and assistance programs. As a result, disabled people will have greater freedom to mix at least some benefits and earned income.

This law does not resolve all employment disincentive problems encountered by disabled people. But many disabled recipients of DI and SSI will find that the legislation greatly enhances their work and supports their rehabilitation.

Illustrating the Point

There are four major disincentive provisions for those receiving Disability Insurance. The descriptions of these provisions will be followed by case examples comparing the effects of current regulations and the new law.

1 Trial Work Period Extended To 24 Months

After nine months of trial work activity, Social Security reviews a DI recipient's disability status. (A trial work month is any month in which at least $75 is earned; the nine months *do not* have to be nine consecutive months.) If the recipient grossed $300 or more in any one month, Social Security determines that he has performed Substantial Gainful Activity (SGA).

The next time the disabled person earns $300 or more in a month, the three-month process to end the DI award and eligibility for Medicare and any social services begins. PL 96-265 allows the disabled person to be technically eligible for DI for 12 more months after complete termination.

During this period, the person receives no cash award, but retains eligibility for Medicare and social services. Moreover, during the additional 12-month period, the disabled person could automatically regain a full DI cash award if his earnings fell below the SGA level.

2 Medicare Coverage Extended For Three Years After DI Cash Award Ends

After Social Security decides to stop a DI cash award because a recpient performs Substantial Gainful Activity, the new law keeps the disabled person eligible for Medicare for three more years. This provision applies only so long as the person does not recover from his or her disability.

3 Income Used For Impairment Related Work Costs Not Counted When Eligibility For DI Determined

When working, a disabled person often needs to spend part of his earnings on attendant care, medical devices, equipment, or drugs and services needed to control a disability. (An example of the last is insulin needed on the job by a diabetic.)

Social Security will no longer count any earnings used for these expenses when determining whether or not a disabled person is performing SGA. These costs will be disregarded even if the items paid for are also needed by the disabled person in normal daily functions.

For instance, the full cost of long leg braces used at work can be disregarded even if the braces are worn outside of work. Similarly, the full cost of insulin medication can be disregarded even though only part of the medication is utilized during work hours.

This disregard, furthermore, can also be used by persons applying for DI benefits as well as those already receiving them. Thus some disabled persons presently working and not receiving any disability insurance may be able to qualify for DI if they are devoting a portion of their earnings for impairment related work costs.

4 Successive Waiting Periods For Medicare Eliminated

Sometimes a former DI recipient needs to regain cash assistance and Medicare coverage. Often, in the past, even when disabled persons successfully reestablished eligibility for DI, they waited five months for the cash award to begin and another 24 months for Medicare coverage to commence.

The new law eliminates this second 24-month wait for Medicare, *provided* the disabled person had waited 24 months for Medicare the original time he or she became eligible for the coverage.

An additional restriction: This provision applies for only five years after a disabled worker loses DI eligibility, and seven years for disabled widow(er)s and adults disabled since childhood.

To illustrate the impact of the new law, consider four disabled persons who have not yet worked while being DI recipients: An amputee, a deaf person, a paraplegic, and a quadriplegic. Each can enter a 12-month training program paying $425 a month and, hopefully, leading to a job with starting pay of $525 a month.

Under the old Social Security regulations: Each of the four persons would have DI, Medicare, and any social service benefits terminated by the end of the training program—*whether or not* they obtained a job placement. Those deciding to take the program risk 1) total cessation of benefits in 12 months, and 2) a five-month wait for DI benefits, followed by a 24-month wait for Medicare should they need to resume benefits.

Under the new law: All four recipients can enter the training program without risking eligibility for benefits. At the end of the 12-month program, the deaf person, and the paraplegic will terminate the DI cash award; but each remains DI eligible and also maintains Medicare and social services coverage.

Because the quadriplegic pays $200 each month in impairment related work costs, he grosses less than the SGA level. His wage ($425) minus his impairment costs ($200) equals $225, which is $75 below SGA, currently $300 a month. The quadriplegic maintains Medicare, social service, and full DI benefits.

After the training ends, suppose the amputee obtains no job placement. His full DI benefit recommences and will continue until he again performs SGA.

If the deaf person obtains a job placement grossing $525 a month, he will continue to earn above the SGA level. After 12 months on the job, he loses his ability to automatically recommence DI benefits. At that point, he also loses eligibility for any social services; but he continues to have Medicare coverage for two more years. (These two years, plus his first year on the job, total the three years of extended Medicare coverage provided by PL 96-265.)

Suppose the paraplegic also gets a job grossing $525 a month. But after six months, his disability is aggravated and his endurance is low. Deciding to reduce his workload to a part-time position paying $250 a month, the paraplegic then recommences full DI beneits. His Medicare coverage reverts back to unlimited status, but he has used up six months of the three years of extended coverage provided by PL 96-265.

Regarding the quadriplegic, let us suppose that in accepting a job paying $525 a month his impairment related work costs increase from $200 to $230 a month. Thus his income for the purpose of determining SGA is $295, $5 below the SGA level. ($525 (wage) – $230 (impairment costs) = $295, which is $5 less than $300, the SGA level.)

While working, the quadriplegic maintains all the benefits he received when he did not work. Keep in mind, however, he retains these benefits only because he devotes one-half of his *gross* earnings to impairment related work costs.

Now, let us say a year later, the quadriplegic declines a promotion paying an extra $50 a month. He reasons that the extra gross is too little to trade for ending the DI cash benefit and starting the three-year clock of extended Medicare coverage. But a year after this, another promotion paying an extra $150 a month is attractive.

The first month he works at the new position paying $675, the quadriplegic loses DI and social service benefits. Because he has previously worked at least 24 months (the full length of the extended Trial Work Period), he *is not* eligible for automatic reinstatement. Still, he has two years of extended Medicare coverage remaining to him.

Administrative Regulations

Before disabled persons can take advantage of PL 96-625, Social Security must draft administrative regulations, i.e. guidelines for how the law will be put into effect. The process should take about six months to complete. Hopefully, in October, interim regulations for the provisions mentioned above will be published, giving consumers and advocates 60 days to review the proposed regulations and suggest changes.

Most of the time, the language of the law clearly specifies how the law is to be administered. In one critical area, however, this is not so. Regarding the exclusion of impairment related work costs, Social Security will have discretion in determining what items, services, and devices are excludable and what is a reasonable value for each exclusion.

Differences of opinion about medications to control diabetes or hypertension are not likely. But concensus on expensive equipment only partially utilized at the job site—for example, an automobile and the accompanying insurance and maintenance costs—may not come easily.

Even though the "Social Security Disability Amendments of 1980" have now become law, much of the work is still to be done. As is well remembered from Section 504 of the Rehabilitation Act, little is done until the regulations covering the law are signed.

Still, there will be changes made which provide opportunities for fuller participation in employment. As always, the final responsibility for getting one's full entitlement under the law rests with the individual involved. Disabled people should learn this law well.

—Robert Gorski

Mr. Gorski is the new associate editor of "Disabled USA."

Ed Note: *The second article in this two-part series will examine provisions of the law affecting the Supplemental Security Income program.*

We invite readers with specific questions on the law to write "Disabled USA" (address on back cover). If we get enough letters, Mr. Gorski will write a follow-up story responding to specific questions.

We also welcome thoughts on how regulations covering the law should be written, especially examples of services, devices, and other items which should be considered "impairment related work costs."

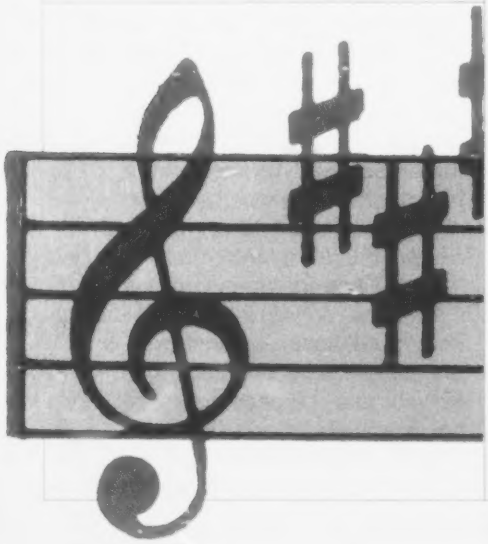
The Chairman's Column

BRAILLE MUSIC . . . Dictionary of Braille Music Signs, the only reference work of its kind for blind musicians using braille music notation, has just been published by the National Library Service for the Blind and Physically Handicapped of the Library Congress.

The book, 210 pages in large print, was prepared by Betty Krolick of Champaign, IL, a music braillist and consultant. It contains definitions of more than 400 music signs and about 100 literary abbreviations.

There are explanatory sections on the history of the braille music code and fundamentals of braille music notation. Signs defined include those used in current transcription and obsolete signs that appear in older music.

The *Dictionary* can be used by braille music readers to determine meanings of unfamiliar braille symbols. Each page of the print edition lists corresponding pages of a companion braille edition. In this way, sighted teachers and blind students can easily locate the same information.



The *Dictionary* is available free to blind musicians and music students. It will also be provided for music teachers, libraries, and schools serving blind music students.

Interested persons should write to the Music Section, National Library Service for the Blind and Physically Handicapped, Washington, DC 20542.

INTERNATIONAL YEAR . . . The President's Committee is one of 215 National partners that have to date endorsed the U. S. Council for the International Year of Disabled Persons (IYDP) in 1981. The Council's mission is to promote the full participation of citizens with disabilities in the life of our society.

To further this mission, the U. S. Council has launched the Community Partnership Program. The Council urges communities to form IYDP community partnership committees to develop locally appropriate goals and short-term and long-term programs to achieve them.

Committee membership should include disabled persons, members of their families, representatives of our local chapters, and individuals from both private and public sectors.

The U. S. Council is providing support and guidance to the Community Partnership Program. Information packets are being sent to local officials' liaisons, and to each of the Council's IYDP National Partners.

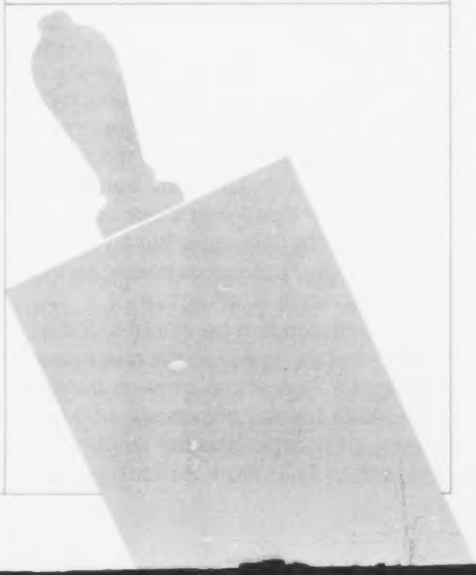
The kit contains background information, a guide to working with the media, suggestions for committee formation and projects, guidance on goal setting and applications for recognition.

We urge our members to become actively involved in this important effort, not only at the community level in cooperating with the IYDP Community Partnership Programs, but at the State level, where your support is critically needed.

To form an IYDP Community Partnership Program, contact: Frank Harrington, Program Director, U. S. Council for IYPD, 1575 "I" Street, N.W., #430, Washington, DC 20005.

COOKING . . . A comprehensive handbook is now available on how to organize and conduct nutrition and cooking training for chronically mentally ill adults. It was developed in cooperation with the Mental Health Center's Community Support Program in Jefferson City, Colorado.

Through an Adult Basic Education grant from the State Department of Education, the Colorado State University Extension Service in Jefferson City conducted a nine-month pilot program to teach basic cooking, nutritious meal planning, and grocery buying skills. A handbook, developed as part of the project describes the objectives, costs and educational methods for working with this special group.



Flexible teaching plans, menus, recipes, nutrition, and food buying information are also covered.

The free handbook will be available in August, 1980. To order, write: Lavonne Barngrover, CSU Jefferson County Extension Services, 15200 West Sixth Avenue, Golden, CO 80401.
(303) 279-4511

ABLEDATA . . . A significant new program—ABLEDATA—is under way at the National Rehabilitation Information Center (NARIC). Working with the California Department of Rehabilitation and Rehabilitation Engineering Demonstration Units, NARIC is initiating an online computerized data bank of equipment and devices for disabled people.

For each aid or device described in the computerized data bank, information is provided on availability, cost and use. Evaluation and user feedback data is included where available. Selected index terms or descriptors from a specially developed controlled vocabulary are assigned to each record.

The data will be operational by the end of August 1980, with the first 1,000 items on personal care, home management, and communication aids. During this initial period, the system is being used on a test basis by the State of California's rehabilitation engineering information brokers.

The full ABLEDATA data bank describing approximately 10,000 aids and devices for handicapped people is expected to be completed and internationally available via computer terminal within this year through the Bibliographic Retrieval Service.

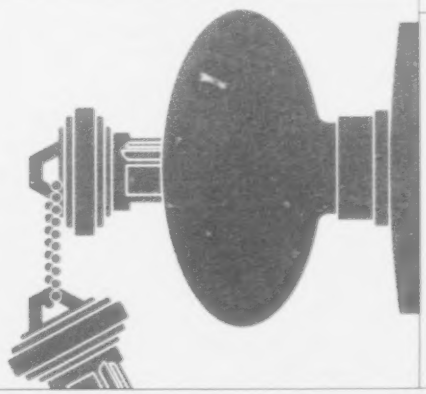
Printed by-products such as listings and catalogs are also planned, and a pre-packaged set of manufacturers' and distributors' catalogs on microfiche, coordinated with the computerized system, will be available.

For more information, contact: National Rehabilitation Information Center, Eighth and Varnum Streets, N.E., The Catholic University of America, Washington, DC 20064
(202) 635-5826 (voice and TTY).

METRO WASHINGTON . . . The George Washington University, Office of Services for Students with Disabilities, recently did a survey on accessible housing. They published a listing, "Accessible Housing Guide for the Washington Metropolitan Area" (District of Columbia, Maryland, and Virginia).

The list doesn't meet specific standards, but reflects locations at which disabled people with differing disabling conditions have lived.

To receive a copy, or more information on the survey, write: Office of Services for Students With Disabilities, Rice Hall, Room 410 George Washington University, Washington, DC 20052,
(202) 676-6710 (voice)
(202) 676-6713 (TTY).



PATIENT'S RIGHTS . . . A National Conference on Patient's Rights will be held September 29-30, 1980, at the Opryland Hotel in Nashville, Tennessee. The conference is sponsored by the American Society of Law & Medicine.

It is open to physicians, nurses, hospital administrators, patient advocates, attorneys, social workers, and others interested in the growing movement to recognize and implement the rights of health care consumers.

The program will discuss patient's rights, patient bills of rights and patient advocates, refusing treatment against medical advice (including life-saving treatment), and indigent patients' rights to "free" health care, among other topics.

The registration fee is $125 for members of the American Society of Law & Medicine, and $145 for non-members. The fee includes a volume of conference materials and luncheon on both days. Advance registration is required.

To register, send your name, address, and registration fee to: Conference Registrar, American Society of Law & Medicine, 520 Commonwealth Avenue, Boston, MA 02215.
(617) 262-4990.

Harold Russell

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DISABLEDUSA

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Special Summer Intern Programs—In the Office, On the Beach . . . People With Facial Disfigurements . . . Part Two of an In-Depth Look at the "Social Security Disability Amendments of 1980"

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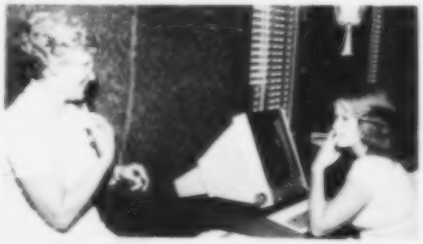

CARDEROCK NAVAL RESEARCH CENTER: A SPECIAL SUMMER INTERN PROGRAM
For a group of 40 disabled high school and college students, last summer was a learning and job training experience at a naval research facility in Maryland. This was the sixth summer that this increasingly popular program occurred, this year choosing from over 100 student applicants.

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ART CREDITS: Cover, pages 14, 15 and 16, Jeri Lucas.

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DISABLED USA reports progress in opportunities for all handicapped workers, keeps Governors' and Community Committees informed of new ideas and activities, and provides all readers with general information concerning developments in rehabilitation and placement of people with disabilities. In a phrase, Disabled USA presents the case for disabled adults.

The Chairman of the President's Committee on Employment of the Handicapped has determined that the publication of this periodical is necessary in the transaction of the public business required by law of this Agency. Use of funds for printing this periodical has been approved by the Director of the Office of Management and Budget through August 15, 1981.

DISABLED USA encourages the submission of articles for publication by all readers, especially disabled people. Articles should be eight to ten, typewritten, doubled-spaced pages, written in an informal style. We also welcome letters from readers for the RSVP column. (All articles appearing in DISABLED USA may be reprinted with or without credit.)

People With Facial Disfigurements

New Surgery Brings Hope to Those Long In Hiding

Being good looking is often one's automatic passport to being popular and well liked. It also has other advantages.

One independent study showed that better medical treatment was given to good-looking patients. Another study found that teachers prejudged better-looking students as high achievers while judging others as average or low achievers.

And a third study showed that college interviewers were less likely to accept overweight applicants even though their qualifications were as good as applicants of normal weight. It's obvious from these studies that appearance does make a difference!

If, indeed it is advantageous to be good looking, what must it be like for people who have severe facial deformities?

"Facially disfigured people have been in hiding for years," states Dr. John Converse, Director of the Institute of Reconstructive Surgery in New York City. "It used to be that facially disfigured people would only go out at night. They were afraid to be seen. Even today, many facially disfigured people isolate themselves because they are often regarded as 'monsters' or 'freaks'."

Chris Winne, a former patient and now a summer employee at the Institute, spent many agonizing years in social isolation because of her facial disfigurement. Her story is typical of others with facial disfigurements, except that her story is happier than some because she was finally able to get help.

Winne's face was grotesquely deformed by a birth defect known as Crouzon's disease. Before the 17 operations needed to correct her features were completed, Winne's appearance was characterized by bulging eyes, a depressed midface, and a malformation of the lower jaw.

The operations didn't begin until Winne was 14. It was at that time that her parents brought her to a plastic surgeon who referred them to the Institute. Before this time she had been told that there was nothing that could be done to help her.

When asked if she had difficulty deciding about the many surgical procedures necessary, and the years of waiting to see results, Winnie responded without hesitation. "I didn't think twice about it—I chose surgery, of course! Going through all that surgery couldn't be any worse than living with my deformities."

Because of Winne's deformed appearance during her childhood, she became withdrawn from her schoolmates and had very few friends. "As early as I can remember," she explained, "the children would make fun of me. Adults would stare at me with pity in their eyes. Even as a small child, the pain was unbearable."

Talking with Winne, it was hard to believe that this young woman with such a lively and outgoing personality could ever have been so withdrawn and without friends. I took an immediate liking to her and found myself envying her determination and strong will.

Winne explained that as the numerous surgeries returned her features to a "normal" appearance, her personality took on a new image. She became more and more sociable and, as she admitted, "A whole new life has opened up for me."

Several years ago Winne got married. And three years ago, she gave birth to her first child. Her son, John Richard, (J.R.), also has Crouzon's disease.

"I was never told the disease was a genetic deformity. I guess I didn't take the news about J.R. too bad, though. Unlike my parents, I know that there's help available.

"Fortunately J.R. is only mildly affected by the disease. But knowing that it's hereditary, no, I wouldn't have another child. I wouldn't want him to go through what I went through." (J.R. has already undergone an operation and has others planned for later in his development.)

In addition to going to college to become a nurse with an interest in rehabilitation counseling, Winne has been working at the Institute. She is presently helping to accumulate information on attitudes toward facially disfigured people.

For Christian Winne, the years of isolation and pain are in the past. But for many others, misinformation and misunderstanding still make them social outcasts.

Like many people who have a disability, facially disfigured persons are subjected to many stereotypes and stigmas. One of the most common is that facially disfigured people are mentally retarded.

"Even some obstetricians are guilty", Dr. Converse explained. "They see a child born with an abnormal face and immediately associate it with mental retardation." Thus, many children have been incorrectly labeled mentally retarded, and institutionalized since birth.

In the past, many people born with these types of birth defects died shortly after birth or early in life. Now, because of the improvement in medical care, facially disfigured persons usually have normal life spans.

The media, when it does acknowledge facially disfigured people, which is not too frequently, usually gives a distorted view of the real facts. Many television programs present scarred or ugly patients turning out to be beautiful after "miracle" plastic surgery is performed.

"That's not the way it is!" Chris Winne explained. "A lot of parents with disfigured children come in thinking that way. Some believe that after surgery they will have super-beautiful kids."

Another problem is that many parents think plastic surgery is a cosmetic procedure, like a face lift. They are not aware of the complex nature of such surgery.

For many patients, plastic surgery is often necessary to sustain such life functions as breathing, sight, and speech. It takes a lot of explaining and counseling before many parents, and sometimes the children themselves, realize this.

The birth of a facially disfigured child is a traumatic jolt to the parents. "First, the parents will go through a whole series of emotional traumas," stated Professor Frances MacGregor, a research scientist in this field. "And how the parent copes with the situation reflects on how the child reacts.

"Many parents have dreams and hopes of their child looking perfect after surgery. And these dreams are not always realized. Plastic surgery takes a period of years and a series of operations for most of these children.

"There is also a tremendous affect on the child's siblings," MacGregor continued. "A deformed brother or sister is often embarrassing. To avoid this embarrassment, the siblings don't bring their friends home. One child even hid her younger brother who was deformed in the closet when friends came over.

"Sometimes, too, siblings resent their brother or sister. This happens because parents often give the facially disfigured child more attention."

MacGregor commented on another problem: "When talking about disability groups, facially disfigured persons are totally left out." One of the reasons for this is that people with facial deformities are still a rare occurrence.

Several diseases and conditions cause a facial deformity, some much more severe than others, but it is difficult to give any kind of incidence figure for this population. And for years this disabled population was made up of individuals in isolation. Only recently have support groups begun to be formed.

In the last year, support groups have been started at the Institute to help families cope with many of their problems. "There has always been a need for these groups in the past," stated Sarah Ellis, a psychologist at the facility, "but we have never had the staffing to do it."

The Institute is now in the process of forming a craniofacial parents' organization called "About Face." The group has had several meetings already.

Much of the discussion centers around the parents' concern about handling the problems of a disfigured child and the impact on the entire family. Other topics of discussion are the difficulties which facially deformed children have in relating to others and the affect which disfigured children have upon their siblings.

Recently, at the Institute, a workshop was organized for facially disfigured teenagers and was run by two former patients. Christine Winne was one of the leaders of the workshop.

"Adolescence is a difficult period for a 'normal' child," Winne commented. "Can you imagine what it's like for a

child with a facial disfigurement? These kids have a lot of questions, and they find comfort in sharing their thoughts and feelings with each other."

Like Winne before her operations, many of these teenagers are withdrawn and unsociable. "We try to incorporate a lot of assertiveness training into the workshops," she explained. "The kids really need it.

"Nowadays, things are better," Winne continued. "There are procedures done on children that used to be done on teenagers. This really saves a lot of psychological trauma on the kids. It seems that when the kids are operated on early, they adjust better than most of those who don't begin operations until their teens."

Another area of Winne's workshop discussion is the vocational aspirations of the teens in the group. "We discuss some of the jobs the kids would like to do. Then we talk about some of the problems they'll first encounter in getting the job. Finally, we discuss on-the-job problems. For example, if one of them wanted to be a receptionist, we'd talk about the strong possibility that they wouldn't be hired."

"For facially disfigured persons, the chances for employment are nil," Professor MacGregor stated. She also commented that many disfigured people have vocational skills, "but nobody wants to hire them because of their appearance." MacGregor added, "Many of these people develop a lot of psychological problems because of the employment problems they encounter."

Many of the facially disfigured youth feel that they won't have any problems finding a job. "This of course isn't true, unless they want to work in a backroom where they can't be seen for the rest of their lives," Winne stated. "At the workshop we try to at least make the kids aware of the problems they will face."

Marjorie Huggins, who works in the Institute's finance and social service section, relayed some other problems facially disfigured patients and their families encounter:

"The financial burden of corrective surgery is incredible. Insurance usually covers most of the treatment costs, but there are other expenditures which accumulate.

"Besides the surgical costs, transportation and lodging expenses are exorbitant. The patients come from all over the world, so this is an additional hardship for any family member or friend who might want to accompany the patient.

"Aid is available to families to alleviate of these costs," she continued. "The Crippled Children's Services offers assistance for medical and transportation expenses. Also, many patients receive funds from private contributions which helps considerably.

"If the patient is young and in school, sometimes we have to contact the school personnel. We discuss with them some of the problems the child might encounter. However, many of these children don't participate in school.

"They don't feel free enough to say what they want in front of others. This often creates problems in their performance and acceptance by others. If patients are of working age, we refer them to vocational rehabilitation. Rehab then tries to aid them in finding a job."

According to Dr. Converse, the Institute is the largest installation of this type in the world. Since its opening in 1963, the Institute has grown to have a staff of about 30, with several other professionals acting as an auxiliary staff.

When patients arrive at the Institute for the initial visit, they are seen by a team of doctors and other professionals. At this first meeting the doctors diagnose the condition of the client and the type of treatment best suited for that individual.

This evaluating process is often quite difficult because many craniofacial disorders are very similar. In addition, many patients have a mixture of different types of disorders which makes the diagnosis that much more difficult.

After the initial visit, a plan of treatment is established for the facially disfigured patient. The disease or condition, and the severity of it, determines the extent of surgical operations necessary and the number of years it will take before features are reconstructed to a presentable appearance.

"Unfortunately," stated Christine Winne, "many disfigured people still don't know that these services are available to them. They go on thinking that nothing can be done."

All the services of the Institute are available to the facially deformed person. The entire rehabilitation process occurs smoothly and with the least amount of trauma possible.

The Institute is one of the few places available to facially disfigured people who need help. But their total care program is bringing hope and help to those who previously had neither. Many people have been reached and are now able to join the mainstream with confidence.

Support groups have been shown to be useful aids in allowing facially disfigured persons and their parents to express the thoughts, feelings, and problems which they encounter in daily life. Talking about similar problems and sharing feelings is often a great comfort to many who feel that their problems are unique.

The only support groups for facially disfigured persons (of which we are aware) are at the Institute of Reconstructive Plastic Surgery at New York University Medical Center in New York. But, it is possible to initiate support groups in other areas. Even in a rural area, it may be possible to begin a small support group or, as an alternative, develop a correspondence with another facially disfigured person.

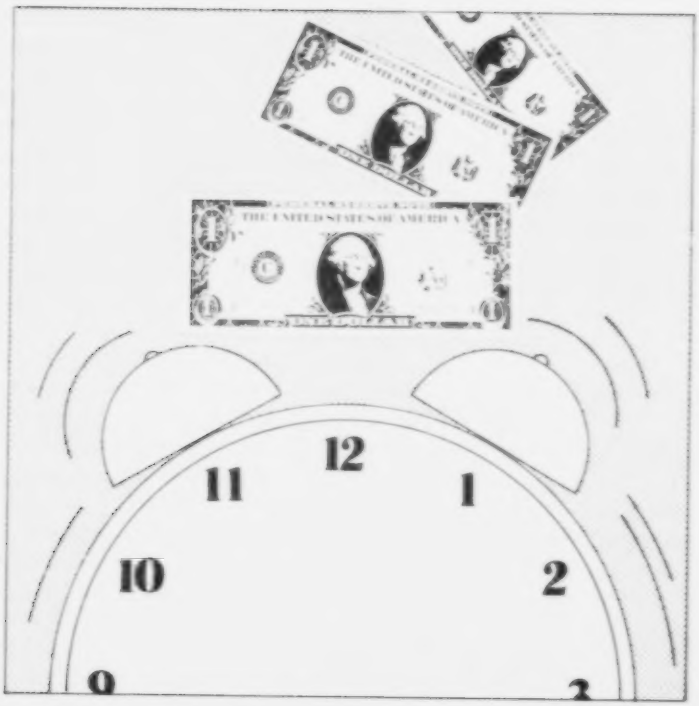
For more information about the support groups offered at the Institute, and information on how to start similar groups, contact Sarah Ellis, About Face, c/o Institute of Reconstructive Plastic Surgery, 550 First Avenue, New York, NY 10016.

—Ellen Blanchard

Ms. Blanchard is a graduate student at Gallaudet College. She did a summer internship in the Communications division of the President's Committee.

New Social Security Amendments Provide Work Incentives for SSI Recipients

This second article, in a two-part series on changes in federal benefit programs for disabled persons, looks at how a new law alters the rules governing the federal portion of the SSI program.



Since its inception in 1974, the Supplemental Security Income (SSI) program has often treated disabled persons who work as if they were criminals. Disabled people have spoken of taking employment as "committing work" because Social Security has exacted substantial financial penalties on the SSI recipient who worked.

According to Social Security regulations, a few months of work activity, even at relatively minor amounts of earnings, rendered an SSI recipient no longer disabled in the eyes of the law. Eligibility for SSI ended, as well as eligibility for Medicaid and Title XX social services.

As a result, many disabled persons chose to stay at home or take low-paying, part-time, and intermittent work. It was not because they didn't want better jobs. Rather, the regulations forced otherwise capable people to be underproductive. Taking full-time work or continuing at part-time work was risky—the loss of financial, health, and personal support benefits could be devastating.

At the heart of the matter was an all-or-nothing situation in the law. You qualified as disabled because you were impaired, poor, and inactive. Then you received full benefits. It was not possible to be impaired and receive *some* benefits to supplement earnings; if you were not qualified to receive *full* benefits, Social Security would not allow you *any* benefits.

Legislation recently passed by Congress and signed by the President does much to alleviate this all-or-nothing situation. PL 96-265, entitled "Social Security Disability Amendments of 1980," contains provisions which will affect the SSI and related programs (Medicaid and Title XX social services) by January 1981.

While reviewing the following descriptions of these work incentive provisions, several complicating factors should be kept in mind.

First, in many States, the SSI payment a disabled person receives is actually made up of some State and some federal money. PL 96-265 changes only the law governing the *federal* money. This article will therefore only examine the effects the law will have on the federal portion.

Second, while certain provisions of the new law are permanent, several important changes are limited to a three-year test period. In 1983 Congress will have to re-authorize these provisions, or else they will no longer be in effect.

Third, the concept of "countable income" plays a key role in the most important of the new work incentives. Put briefly, countable income is a person's earnings minus certain exclusions allowed by prior law and additional exclusions allowed by the new law. Social Security uses countable income to compute the amount of an individual's SSI award.

There are eight major work incentive provisions affecting the SSI and related programs (Medicaid and Title XX social services) in PL 96-265. (Following the descriptions of these provisions will be several illustrations of how these provisions will assist disabled people in making a decision about work.)

I. *Impairment-related work costs excluded from substantial gainful activity determination test*

(A permanent change effective January 1, 1981.)

Substantial gainful activity (SGA) is a part of the disability test for SSI. To qualify as disabled for SSI, a person must have a certain level of physical or mental impairment which prevents him from performing SGA. Currently, SGA is defined as $300 a month in gross earned income. Income at or above this level is evidence that a person is not sufficiently impaired to qualify for SSI.

Social Security uses the SGA test when a person applies for cash assistance and whenever an SSI recipient obtains income. Thus, one way for an SSI recipient to terminate his cash award is to earn income at or above SGA level.

When working, a disabled person often needs to spend part of his earnings on attendant care, medical devices, equipment, or drugs and services needed to control a disability. (An example of the latter is medication a person with epilepsy needs to control seizures.) Up to now, in most cases all of a person's income has been considered when Social Security applied the SGA test.

PL 96-265 makes an important new exemption by excluding from consideration earnings used for impairment-related work costs, even if the items and services paid for are also used in daily living.

For instance, the full cost of long-leg braces used at work can be disregarded even though the braces are worn outside of work. Similarly, the full cost of epilepsy medication can be disregarded even if only part of the medication is utilized during work hours. (Nevertheless, the Secretary of Health and Human Services will define by regulation precisely what costs are excludable and the maximum value allowed for each.)

II. *New formula for computing amount of SSI benefits*

(A permanent change effective January 1, 1981.)

Earned income *reduces* the size of the SSI payment for which a disabled person is eligible. The formula for determining the amount of reduction takes the gross wage and subtracts certain allowable exclusions. The remainder is called "countable income."

This countable income is subtracted from the standard federal cash award. The standard federal cash award (currently $238) is the maximum federal amount a disabled person can receive under SSI. This determines the actual payment. To illustrate: A gross wage of $485, minus all prior standard deductions, results in a countable income of $200. This, in turn, yields an award of $38 of *federal* SSI.

PL 96-265 adds a new exclusion to the benefit computation formula. For the first time, SSI recipients who work will be able to exclude nearly all impairment-related work costs from their gross wages.

This will produce a lower, more realistic calculation of countable income. By lowering the amount of countable income, a recipient increases the amount of his SSI award: Every $2 of income devoted to impairment-related work costs will help the SSI recipient retain an extra $1 of SSI. The new formula for computing this federal SSI benefit is as follows:

1) Gross earned income minus $65; 2) Minus another $20 if the recipient has no "unearned" income from pensions, alimony, disability insurance, etc.; 3) Minus impairment-related work costs; 4) If the recipient is blind, minus the cost of other work expenses; 5)

Divide by two; and 6) Subtract the remainder from the standard SSI benefit. (Note: If the recipient has unearned income, a different formula is used.)

Using this formula, let us again take the example of the disabled person (who is not blind) who has a gross wage of $485. First, the wage earner makes the standard deductions of $65 and $20. If $100 of the wage is spent on impairment-related work costs, this is also deducted. This figure of $300 is then divided by 2 and deducted from the standard Federal cash award of $238.

Therefore, under the new amendments, the federal SSI award would be $88 instead of $38.

III *Special benefit SSI for persons earning above SGA*

(Effective for a three-year test period beginning January 1, 1981.)

Under the new law, when Social Security ceases an SSI award because the recipient has performed Substantial Gainful Activity, the recipient automatically becomes eligible for a new category in the SSI program, called "Special Benefit." A disabled person in Special Benefit status receives a special cash award equal to the standard federal SSI benefit, minus the person's countable income.

By receiving at least $1 of Special Benefit SSI, the person secures eligibility (on the same basis as a recipient of regular SSI) for whatever Medicaid his State provides recipients of regular SSI. In addition, the person with a Special Benefit award is eligible (on the same basis as a recipient of regular SSI) for the Title XX social services his State provides recipients of regular SSI.

Persons are ineligible for Special Benefit status when their countable income equals or exceeds the standard Special Benefit allowed in their State. (Remember that States are free to supplement the basic federal award of $238.)

Thus, in some States, disabled persons with only $238 of countable income will drop out (or never get into) Special Benefit status. In other States, the figure could be up to $300 or even higher. Ending the Special Benefit also ends eligibility for Medicaid and social services on the same basis as a recipient of a regular SSI cash award.

IV *Continued Medicaid and Social Services*

(Effective for a three-year test period beginning January 1, 1981.)

When countable income is too high for even Special Benefit eligibility, some disabled persons still have critical needs for Medicaid and social services benefits. A provision of PL 96-265 addresses this situation by creating what advocates are calling a "Special Medicaid" status.

In this status, the disabled person does not receive any cash award, but can become and remain eligible for Medicaid and social services by meeting two conditions:

First, loss of medical and social services benefits must seriously inhibit the individual's ability to continue his employment.

Second, the individual's earnings must be insufficient to provide a reasonable equivalent for the lost cash assistance, medical coverage, and social services benefits.

Thus, Congress recognizes the fact that some severely disabled individuals have continuing medical treatment, attendant care, and other disability related needs too expensive for their work earnings to finance.

V *Trial Work Period Extended*

(A permanent change effective January 1, 1981.)

Every qualified SSI recipient is entitled to nine trial work months before Social Security can determine whether or not the person has performed Substantial Gainful Activity. A trial

work month is a month in which the recipient grosses $75 or more; the nine months of trial work do not have to be consecutive.

Up to now, after using up the nine month allotment, if the recipient earned at or above the SGA level, the termination process for regular SSI began. The termination process took three months to complete.

In the future, according to PL 96-265, regular SSI payments will be suspended, not terminated. Termination will not occur until 12 months later. And during this time the former recipient of SSI can automatically resume the cash award if his earned income (minus impairment-related work costs) falls below the SGA level.

This so-called "extension" of trial work is inconsequential to recipients in Special Benefit status. But the extension can be quite critical for *some* persons who become eligible for Special Medicaid. And it is especially important, for *all* persons who lose regular SSI but do not gain either Special Benefit or Special Medicaid status.

VI *All Income From Sheltered Work Counted As Earned Income*

(A permanent change effective October 1, 1980.)

Under prior law, Social Security often classified wages and other remuneration from sheltered employment and work activity centers as *unearned income*. In computing the size of the SSI benefit, this disadvantages an SSI recipient in two ways:

First, only one minor exclusion—a flat $20 a month—is allowed from unearned income. This differs from earned income which allows all the exclusions described in Item II above. Therefore, for sheltered work, all of the remainder becomes countable unearned income.

Second, every unexcluded dollar of *earned* income reduces the SSI award by 50¢, but every $1 of countable *unearned* income causes a reduction of one full dollar. Unearned income, therefore, has a great negative impact on the computation of the SSI benefit.

Under prior law, if an SSI recipient in sheltered employment earned $290, that was unearned income. Only a single exclusion of $20 was allowed when Social Security computed the benefit amount. Therefore, the recipient had a countable income of $270. This is higher than the Federal portion of SSI.

In such cases, the recipient would cease any SSI benefit. As a result of this, he would also become ineligible for Medicaid and Title XX social services. The sheltered employment income of $290 would become his only resource for his health, well-being, and impairment-related work costs.

By stating that all workshop and activity center income should be considered *earned* income, PL 96-265 will allow employees to reduce their countable income using all the earned income exclusions listed in Item II above.

The sheltered employee of the previous example can now deduct his impairment-related work costs from his gross income. In addition, he can also take advantage of any other earned income deductions for which he is eligible, such as minus $65, minus $20, minus other work expenses if the worker is blind, and divide by two.

These deductions might keep the employee's countable income below the standard federal SSI benefit. Consequently, he will continue to receive some SSI and remain eligible for the Medicaid and social services his State provides to SSI recipients.

VII *Deeming of Parent Income Changed for Disabled Students*

(A permanent change effective October 1, 1980.)

PL 96-265 reclassifies as adults those SSI recipients between 18-21 years old who attend school or training programs and reside with their parents. Under prior law, these persons were considered to be children. Consequently, a portion of the income of the parents was "deemed" to be countable income for the SSI recipient, and his award was reduced accordingly. In some cases, the reduction was so severe that SSI recipients have been forced to quit schooling and training programs.

PL 96-265 allows parental deeming only when the SSI recipient is under age 18. Nevertheless, as an adult, an SSI student, age 18-21 and living with his parents, may now be liable for a flat one-third reduction in the federal cash award. This reduction is made on the grounds that he is "living in the household of another and receiving support and maintenance in kind."

For some current SSI students, the application of this provision could actually reduce the amount of cash benefit they *presently* receive. Recognizing this, the law makes provision to prevent such reductions: *In such cases, the change in deeming parent income will not apply.*

VIII *Medicaid and Social Services for Non-SSI Eligibles*

(A 37-month pilot project in those States that wish to participate, effective September 1, 1981.)

The new law allows Social Security to experiment with new ways of assisting disabled people to work. One project specifically mentioned will provide Medicaid and social services benefits to severely disabled working persons.

This project is available only to disabled persons who, because of high income, were never connected with the SSI program or are unable to regain former eligibility. Although the pilot project is similar in nature to Special Medicaid status, (See Item IV), there are two important differences.

First, Special Medicaid only helps *recipients* of regular and Special Benefit SSI when their cash awards cease. Second, the pilot project will be effective only in States that choose to participate. Thus, eligibility criteria and benefits can vary from State to State. In contrast, Special Medicaid status is a nationwide program with uniform criteria and benefits.

Illustrations

How the most important work incentives (Items I-V above) will work can be illustrated by considering two SSI recipients who will have parallel work histories as follows:

1) Both persons take jobs paying $200 a month. At this point, neither person has any impairment-related work costs. Earnings of $200 a month translates to $58 of countable income. (Gross wage of $200 minus $65, minus $20, and divided by 2.) Such a low amount does not affect eligibility for SSI, Medicaid, or social services.

Nevertheless, by deducting the countable income of $58, the federal portion of each recipient's award is reduced from $238 to $180. In addition, both recipients begin to use up the first nine-month allotment of their trial work periods.

2) One year later, both persons take jobs paying $385 a month. One of the recipients, Recipient A, still has no impairment-related work costs. His earnings ($385) fail the SGA test by $85. Since the recipient has completely used up the first nine-month allotment of his trial work period, Social Security now begins the three-month process to terminate regular SSI.

But three months later, when termination is completed, the recipient's countable income of $150 ($385 minus $65, minus $20, and divided by 2) is low enough to allow eligibility for a Special Benefit payment of $88.

By receiving a Special Benefit, the person also becomes eligible for Medicaid and social services on the same basis as a recipient of regular SSI. Keep in mind that Recipient A has used 12 trial work months. By continuing to work, he now begins to use up the remaining 12 months of the 24-month trial work period.

Recipient B, the other disabled person with the $385 job, on the other hand, does incur impairment-related work costs totaling $120 a month. Consequently, first of all, because Recipient B's income for the SGA test is only $265 ($385 – $120), he *remains in regular SSI status.*

Second, since the benefit computation formula excludes earnings used for impairment-related work costs, the recipient receives a cash award of $148. (Gross wage of $385 minus $65, minus $20, minus $120, divided by 2, and subtracted from the federal award of $238.) So far, Recipient B has used nine months of his trial work period. By continuing to work, he *does not* use up any more trial work months.

3) Six months later, both disabled persons accept work paying $1000 a month. Recipient A, remember, has no impairment-related work costs, and so his countable income is $458. ($1000 minus $65, minus $20, and divided by 2.)

This is far above, let us say, the Special Benefit award available in the State where he lives. Therefore, he terminates Special Benefit status. Yet, his application for Special Medicaid status is successful, and medical and social services coverage continues.

The outcome for Recipient B is similar. Even excluding his $120 a month in impairment-related work costs, he fails the SGA test by $580. ($1000 minus $120 is $880, which is $580 more than the SGA level of $300.) Because he has used up the first nine months of the trial work period, Social Security begins the three-month process of terminating the regular SSI benefit.

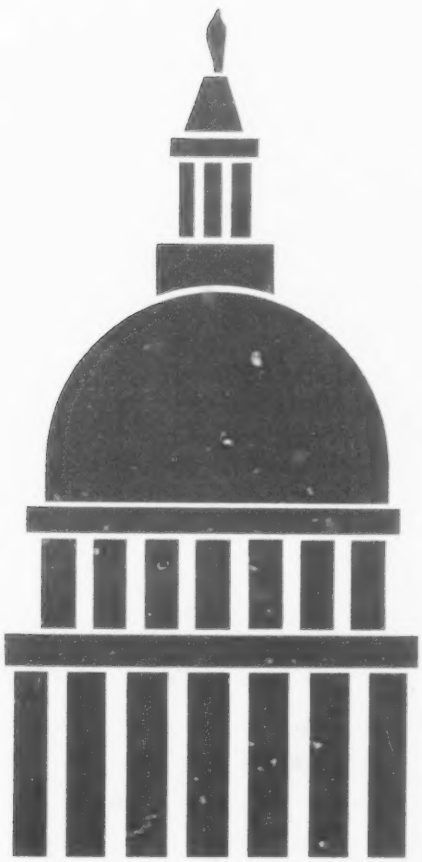
His countable income, even excluding all earnings used for impairment-related work costs, is $398. ($1000 minus $65, minus $20, minus $120, and divided by 2.) This is too high, let us suppose, for him to receive Special Benefit SSI in his home State. Yet, this person also applies for Special Medicaid, and is successful.

4) One year later, both disabled persons have to stop working. The first person cannot automatically resume regular SSI payments, as his "extended" trial work period ended three months previous. To regain an SSI award, he must apply as if he were a new applicant. The other person can resume regular SSI automatically. His regular SSI benefit ceased only nine months previously, and three months of his extended trial work period remain.

Of course, the purpose of the work incentive provisions of PL 96-265 is not to perpetually circulate disabled persons back and forth through different phases and statuses of the SSI program. Rather, it is intended that, given flexibility to mix benefits and earned income, many recipients will significantly reduce their dependency on federal assistance.

Hopefully, when all the regulations are in effect, more and more persons will "graduate" completely and permanently out of benefit programs.

—Robert Gorski



Reflecting On the Legislation

To an observer, the complexity of the SSI work incentives in PL 96-265 might seem to be the product of political compromising. Actually, this accurately reflects the legislative history of the matter.

For years, disabled persons have argued for a fundamental change in the way the Federal government considered disability. Such change, it was argued, should involve a new assistance program for the severely disabled who have high disability costs.

It should also include a substantial raise in the definition of substantial gainful activity (SGA) so that SSI recipients would not face early termination from cash and other forms of assistance.

In PL 96-265, Congress goes a long way toward incorporating the basic changes recommended by consumers. Special Medicaid will obviously be utilized mostly by the severely disabled. It is they who will have substantial disability-related needs too expensive for their earned income.

Special Benefit status, the new benefit computation formula, and the new income exclusion in the SGA test are three provisions that lessen the *impact* of the continuing low dollar definition of SGA. But it is important to realize that the *definition* still is the same.

Congress decided on complex and somewhat round-about solutions to the work incentives problem in SSI. This was done because some powerful members argued that any changes would encourage welfare abuses, cost too much, and not produce any more employment activity.

Because of this steadfast resistance to simple, across-the-board changes in the Social Security law, only legislation designed to provide limited and selective work incentives was feasible. Indeed, even the two most far-reaching provisions (Special Benefits and Special Medicaid status) are rendered tentative by the imposition of a three-year testing period.

Still, it is justifiable to see PL 96-265 as a truly substantial advance in disability legislation. Not only because of the actual content of the law, but also because of the process that brought it about. The legislation, it is important to see, is the product of several years effort on the part of many disabled organizations working closely with members of Congress.

An important milestone in this long process occurred three years ago. The chairman of the House Public Assistance Subcommittee, Representative James Corman (D-California), became acutely sensitive to the incentives problems in SSI.

He arranged a Congressional luncheon for members of the important House Ways and Means Committee and over a dozen consumer advocates from across the country. This luncheon was a kick-off for a bill sponsored by former Congresswoman Martha Keys (D-Kansas) that closely incorporated consumer recommendations on SSI reform.

In the months that followed, disabled advocates spent many days in Washington, DC, lobbying representatives and senators on behalf of the bill. The Keys bill passed the House with over 300 votes aye, and was approved by the Senate Finance Committee in a heavily amended form. But then it was buried in the legislative wheeling and dealing at the end of the 95th Congress in October 1978.

When the 96th Congress convened in the winter of 1979, Congressman Corman again spearheaded the legis-

lative effort by introducing a comprehensive SSI reform bill in the House.

On the Senate side, Senator Robert Dole (R-Kansas) also introduced a comprehensive reform bill. Senator Dole, who was also acutely sensitive to the incentives issues, was now the ranking Republican on the Senate Finance Committee. Thus, the consumer viewpoint had generated influential, bi-partisan, and working allies in both Houses of Congress.

As in the previous year, the House bill passed overwhelmingly. The Senate Finance Committee then took the Corman bill, the Dole bill, and many other pieces of social welfare legislation and created a large package bill, the "Social Security Disability Amendments of 1980," which made changes in the SSI program, as well as other programs benefiting disabled people.

All during the final stages of the legislative process, many disabled organizations worked for the most effective incentive provisions possible. Congresspersons and their staffs were constantly aware that this was an important issue to the disabled community, which was closely observing and lobbying for strong reform.

A member of one organization, the Westside Community for Independent Living in Los Angeles, even observed the conference proceedings in the tiny meeting room in the U.S. Capitol. According to Congressional staff, this was the first time that a disabled representative had ever been present at the final bargaining stage in the legislative process.

While some of the incentive provisions are clearly spelled out in PL 96-265, others are not. Administrative guidelines for implementing them will be critical to their effectiveness. Chief among the regulations to be drafted are those describing what are excludable impairment-related work costs, what are the precise criteria for Special Medicaid status, and exactly how the pilot project involving Medicaid and social services coverage will operate.

The active presence of disability advocates had a profound impact on Congress. Hopefully, this effect will continue during the process of writing implementing regulations. This is likely now more than ever before.

Government is more aware that SSI recipients want to work. There is now a knowledge that disabled people will work if there is flexibility in Social Security. But, there must be flexibility in order to maintain cash and other support benefits when they are critically needed.

—Robert Gorski

Brenda Gilmore: The Photographer's Art

Brenda Gilmore is a dynamic young woman who not only enjoys photography as a professional career, but also delights in it as a leisure activity. This accomplished artist dabbles (quite successfully!) in different types of photography, but her specialization involves doing portfolio work for actors, actresses, musicians,and models.

As a result of a hit and run automobile accident a few years ago, Gilmore is a paraplegic and uses a wheelchair. Her disability, however, does not slow her down any.

Recently, some of Gilmore's pictures of children were on display as part of an exhibit entitled, "Unconfined Spirits" at the Martin Luther King Library in Washington, DC. Another exhibit at the same library included some of her pictures of senior citizens.

Gilmore received her photography instruction at Howard University and her practical experience at two major photo labs in the Washington area. She is now on the staff of Arts for the Handicapped in Washington, DC.

—Ellen Blanchard

Ms. Blanchard is a graduate student at Gallaudet College. She did a summer internship in the Communications division of the President's Committee.

Summer Marine Science Program has Disabled Students Hitting the Beaches

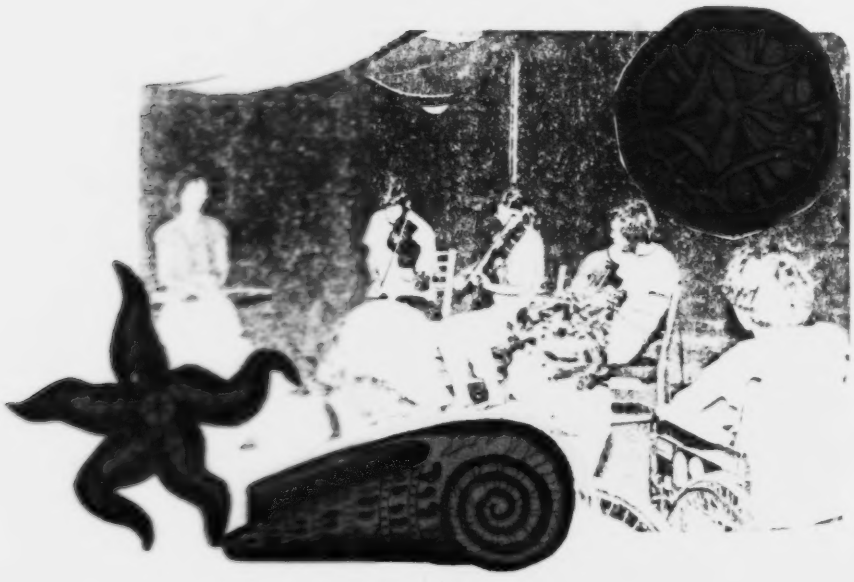
Hearing people singing the song "You Light Up My Life; seeing some of the vocalists "singing" with their hands; being barraged by words like domax, ecology, dunes, salt marsh and barrier island; being blindfolded and asked to identify certain characteristics of different crabs.

These are a few of the different images that I remember. And they are only a small part of my three-day visit to Wallops Island, Virginia.

This summer, 20 young people travelled from across the United States and Canada. They converged on Wallops Island to participate in an intensive, five-week summer program in marine science for physically handicapped students.

The program, funded by a National Science Foundation (NSF) grant and through tuition from the participants, was founded in 1977. Its purpose is to expose outstanding disabled high school juniors and seniors to various areas of marine science. It is a part of the Marine Science Consortium, Inc., which includes 17 colleges and universities from West Virginia, Pennsylvania, Maryland, and Washington, DC.

Class work and field trips are coordinated to give students a well-rounded experience. One of the aims of the program is to show disabled people that a disability does not have to be a deterrent to becoming a scientist. Another goal is to teach students that research is not always glamorous, but, more often, is long, hard, tedious, very important work.



Field trips are opportunities for students themselves to learn how to navigate a vessel, to lower a dredge to collect specimens from the ocean's bottom, and to dig on the beach for the sea life that lodges there. The students also visit the barrier islands to see how the islands protect the mainland from the assault of the waves and wind.

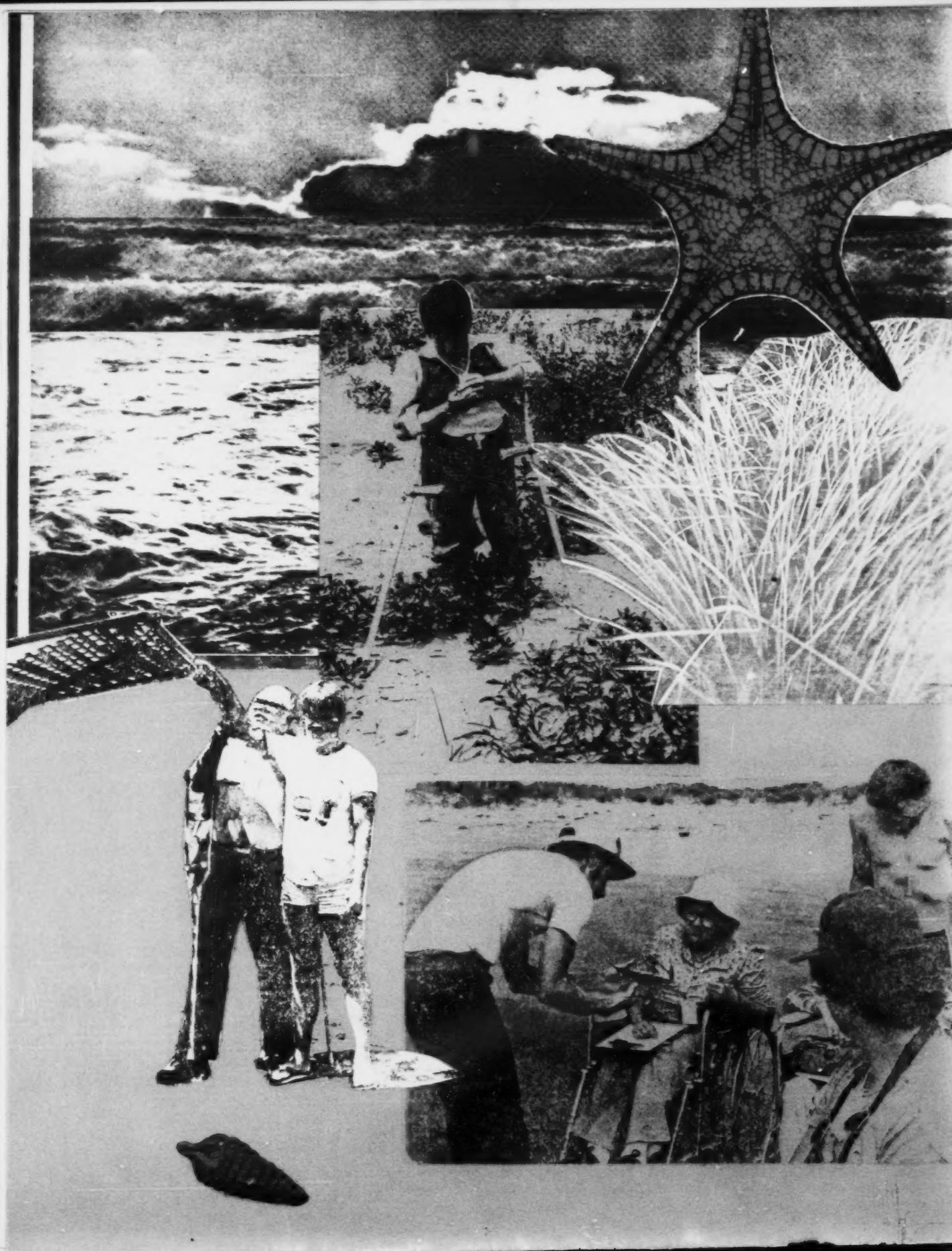
On field trips, students participate in all aspects of marine science. Students are briefed in class the day before on what to expect on the trip, and told to read up on the subject.

The day I was there, the class was discussing how to write up a scientific report on whether domax migrate with the tide. (I learned later that a domax is a small clam.) Previously they had gone to the beach to set up the project and actually observe the domax and the tide.

Since some students were hearing impaired, Paul Cunningham, a science teacher at Gallaudet College Model Secondary School for the Deaf, signed for them. Because no equivalent signs exist for many scientific terms, he is working on a glossary to fill this need.

Readers for the visually impaired students were also available. Tactile boards and braillers were used to reinforce lectures and field trips. Before the class sessions started, all students attended a communications laboratory in order to become acquainted with each other and to learn rudimentary braille and sign language.

Next the instructor lectured on the properties of a salt marsh or bog. (The field trip to the marsh that day was cancelled because of rain.) Some students have mobility problems, like



Debbie Doloto who has spina bifida and sometimes uses a wheelchair. For these students, sections of snow fence have been laid across the marsh to make it accessible.

Along with mini-projects, students are expected to complete a major project by the end of the five weeks. With the help of their counselor, they must choose a project, draw up a hypothesis, do the research, and put their findings in writing.

James Rahuba from Munhall, Pennslyvania, is hearing impaired. His project was searching for the difference between the chemical properties of water in a salt marsh and in the ocean. Rahuba, 17, has attended regular school for three years, and plans to continue studying marine science.

Blind since childhood from glaucoma, 17-year-old Larry Keeler from Kalamazoo, Michigan, chose bird calls of the coastal system as his project. Keeler, who attends the Michigan School for the Blind, is interested in further studies in oceanography.

Measuring in 15 places from the ocean's edge to the high dunes, Kelly King took the temperature beneath the surface of the island to find why some animals can live in certain temperatures while others cannot. He attends the West Virginia School of the Deaf.

Even I played a tiny part in one of the projects. David Hunt, from Medford, Massachusetts, and blind since birth, needed persons with a limited knowledge of crabs to help him set up an identification guide that other blind people could use. Since I have an extremely limited knowledge of crabs, Hunt was able to use me to test the validity of his system.

Many students had no prior interest in marine science. For some, the experience inspired them to continue in this area. Others, like Debbie Doloto, feel that, while they do not plan to continue a scientific career, what they learn will help them in whatever career they choose.

However, 18-year-old Mark Harding from Amherst, Nova Scotia, has loved the sea for years. He plans to attend Gallaudet College to study marine biology. Deaf since birth, he learned lip reading at a public oral school and signing at a school for the deaf.

Besides studying, recreation is an integral part of the program. Before the class started, two students were playing a duet on zithers. When they are not studying, students go swimming, attend dances, go to arts and crafts classes, or just relax.

It was not long before I learned the reason why I heard singing when I arrived. Some of the students were rehearsing songs they would be singing at a banquet given that night for all program participants.

According to Dr. Edward C. Keller, founder and program director, careers in the sciences have largely been bypassed by many disabled students. Many students have been told that the sciences are not for them.

"Then, too, those who take the general science courses are often excused from participating in field experiences. I use one of our instructors, Dr. Thomas S. Austin as a model for our disabled youths to emulate. He has been a paraplegic for 28 years and a practicing oceanographer for 33 years."

Jim Koehler, a program instructor and a wildlife resources specialist, said Wallops Island is a "natural" for this type of program. "It has fresh water and salt water sources. And the myriad coastal wildlife that frequents Wallops, Chincoteague, and Assateague Islands provides abundant material for research."

Cooperative efforts with government facilities, local fishermen, and community organizations allow Dr. Keller, disabled by polio since 18, to organize field trips. The group uses the government-owned beaches to study and local boats to reach the beaches.

"The presence of other college programs on Wallops also provides an opportunity for our students to mingle with able-bodied students and faculty," Koehler explained. "While our program is just for disabled students, there is really no isolation. Other students have become interested in learning signing, as well as socializing with our students.

"Then, too, we encourage groups to come and observe our students at work. We feel this is one way to help science teachers learn the abilities of disabled students. Hopefully, this will cause teachers to exert extra effort toward mainstreaming disabled students in their classes."

Plans for future summer programs include trying to increase the number of participants next year, if NSF or some organization will fund them, and perhaps developing a project to observe whales off Ocean City, Maryland.

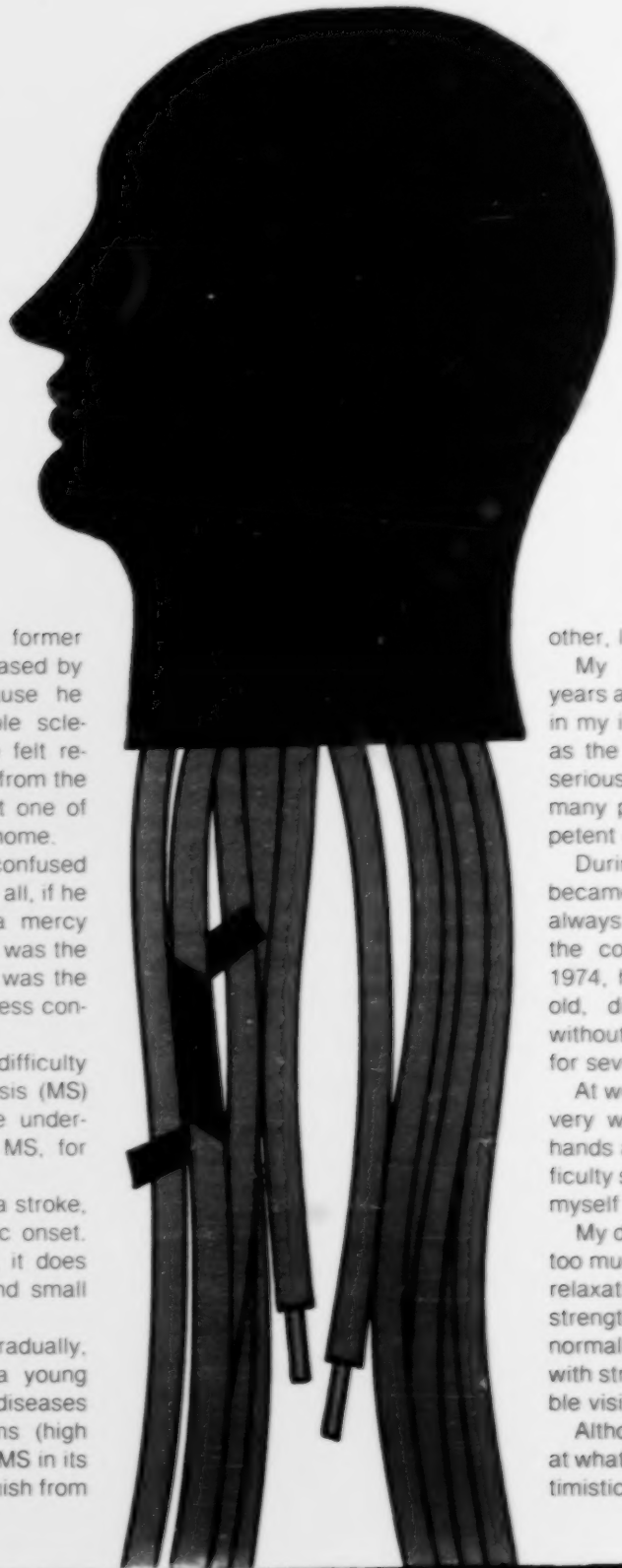
For more information on the Wallops Island program for physically handicapped students, contact Dr. E. C. Keller, Professor of Biology, 237 Brooks Hall, West Virginia University, Morgantown, WV 26506; Phone: (304) 293-4380.

—Juanita Campbell

Ms. Campbell is on the Communications staff of the President's Committee.

Multiple Sclerosis

What Is this Condition We've Been Reading About Lately?



Richard Queen is the former American hostage released by Iranian students because he showed symptoms of multiple sclerosis. Like me, many people felt relieved when he was unloaded from the airplane in Germany: At least one of our countrymen was coming home.

But many people also felt confused about Queen's disability. After all, if he was ill enough to warrant a mercy release from his captors, why was the diagnosis tentative? And why was the patient well enough to hold press conferences?

I was not confused. To me, difficulty in diagnosing multiple sclerosis (MS) and its unusual effects were understandable since I have had MS, for perhaps, over 20 years.

Yes, I say perhaps. Unlike a stroke, MS does not have a dramatic onset. Unlike congenital disabilities, it does not show up when babies and small children are examined.

MS develops, instead, gradually, starting when a person is a young adult. While other chronic diseases have definite early symptoms (high blood pressure, for example), MS in its early stages is hard to distinguish from other, less serious illnesses.

My MS was diagnosed only two years ago. Only then did I see a pattern in my illnesses since the early 1960's as the early stages of a chronic and serious disease. This was so, despite many previous examinations by competent doctors.

During my young adult years, I became quite ill every few years. But I always felt it was nothing more than the consequence of overactivity. In 1974, however, when I was 41 years old, disturbing symptoms occurred without any forewarning and persisted for several months.

At work one day, I suddenly became very weak and felt numbness in my hands and arms. For a while I had difficulty standing and couldn't even drive myself home.

My doctor diagnosed my problem as too much stress and advised complete relaxation. Over that weekend, I felt my strength and coordination return to normal, but I was occasionally afflicted with strong dizziness (vertigo) and double vision.

Although my family was distressed at what was happening to me, I was optimistic. My physical problems came

and went, and I had no pain. So I felt the best way to respond to my doctor's diagnosis was by working normally again.

At the office the next day, I only lasted two hours. Without warning, I became very weak and lethargic, felt dizzy again, and had double vision. This time my doctor admitted me to a hospital where I was tested for all kinds of ailments over a three-week period.

Another symptom now occurred for the first time: Selective memory loss. Little things had escaped my mind, like details about my work or the name of a colleague.

No physical causes for my problems came to light. So the doctor went further into emotional reasons for my illness and decided I was psychosomatic. This meant that some kind of mental conflict was causing my physical problems.

My doctor prescribed a drug called valium that relieves mental anxieties. But my symptoms persisted, coming and going as before. And still there was no sense of pain or even of being really sick.

Now the doctors took a new tack. X-rays of my spine suggested that a disc between two vertebrae had degenerated, so the new prescription was physiotherapy and several months of rest. This appeared to offer real relief and my strength gradually returned to normal, numbness in hands and arms went away, and my walking became steady again.

But I was not entirely free of symptoms. Double vision would occur if I looked up without tipping my head back. Selective memory loss remained, persuading me to leave my work which required recalling details of activity from past months.

Luckily, I found acceptable new work. I was normally active again; and neither I, my family, nor my doctors had any inkling that my problems would surface again four years later and in a more intense form.

In the spring of 1978 all the problems I had in 1974 returned more strongly than before. For example, now paralysis occurred along the entire side of my body. Following a week of testing in a hospital, a consulting neurologist told me my illness was "something like" multiple sclerosis.

I could leave the hospital, he said, but it would be several months before the doctors could definitely say if it was or was not multiple sclerosis. Apparently, MS was so hard to detect, the doctors would proceed to a final diagnosis by ruling out all other possible ailments.

My memory loss was now greater than before, and I was fatiguing easily. When the final diagnosis of multiple sclerosis did come in, I left work on early retirement in order to adjust to my disability and its erratic nature.

Probably Richard Queen didn't have as long a period of misdiagnosis as I had. But I believe the news media did report that Iranian doctors had been examining him for many months. And American doctors took over a week to conclude that it was MS.

So I think that Queen probably experienced at least some of the uncertainty and false optimism I did. People should realize that doctors have a hard time diagnosing MS because of how the disease works inside the body—it is changeable and difficult to perceive.

Multiple sclerosis is not a disease that attacks muscles, bones, or other organs. It attacks something more difficult to isolate and examine: The thin wrapping that encases nerve cells in the body.

Nerve cells are the means by which the brain communicates with the rest of the body, telling the eyes to focus, or the legs to move. The body also uses nerve cells to give the brain information about, for instance, what a finger is touching, or what your memory says your Social Security number is.

Nerve cells should be compared to electric lines for telephone communication. The wrapping around the nerve cells is like the thick rubber insulation around telephone wires. Removing patches of insulation from the telephone line causes "short circuits" and interrupts the flow of electricity.

If you repair those patches with good electrical tape, you eliminate the short circuits and restore normal communication. Using common scotch tape will eliminate shorts only some of the time, and communication will come and go intermittently.

It is the same with myelin cells, the thin wrapping around nerve cells. Something that science does not yet understand makes small bare patches in the myelin, and for a while communication at different points in the body becomes garbled. As a result, some parts of the body function abnormally.

The most common problems are double-vision, uncontrolled eye movements, slurred speech, paralysis, numbness, and fatigue. There can also be tremors in the hand, leg drag, loss of coordination, and loss of bowel and bladder control.

Since the myelin cell is living tissue, it tries to heal itself. If good new myelin grows over the bare spot, communication in that nerve cell is normal again. Double-vision, fatigue, and other symptoms go away.

But if scar tissue forms over the bare patch, problems in nerve communication will still occur. These will probably become permanent problems.

In a person with MS, this process of baring and healing over goes on intermittently, at many different locations in the nervous system, and sometimes even simultaneously. Hence the word "multiple" in the name of the disease. "Sclerosis" comes from the word "sclerosed", which is the technical term for scar tissue.

There is no pattern to which nerves are attacked, when they are affected, and for how long. Thus symptoms of MS come and go, unpredictably and without warning, and differ greatly from one patient to another.

The only experience common to most MS patients is the gradual onset of the disease. Often the early symptoms are so slight that a person decides not to see a doctor. In fact,

they can occur for such a short time that the individual hardly notices them.

Many people with MS have few or no symptoms for months or years. About 75 percent of diagnosed MS patients are still able to take care of their daily needs, continue working, and look forward to a normal life expectancy. The others, unfortunately, must interrupt their careers in order to adjust to a serious, ongoing problem.

Scientists do not understand the cause of MS. Some feel it is a virus; some say it is a case of the body's defense system mistakenly attacking the body itself; others feel it is a combination of both theories.

Whatever the case, there are some demographic patterns about people with MS. Most of them are young adults, more are women than men, and most live in temperate climates. Moreover, MS is more common in areas of high sanitation than in areas with poor sanitation standards.

Professionals may argue about what these demographic patterns mean, but there is agreement that MS is neither inherited nor fatal. But it is a disease that limits what a person can do, when, and under what conditions.

This is why Richard Queen can have MS and still appear able-bodied before the news cameras. Keep in mind that although some MS patients use wheelchairs and walkers, others need only a cane, and not necessarily all the time.

I have a fairly extreme case of MS, so many other MS patients might have similar limitations and ways of adjusting, although perhaps not to the same extent.

My episodes of double-vision and vertigo are brief and normally vanish if I rest. Moreover, shutting one eye immediately ends seeing double, and I have medication to alleviate strong dizziness.

Coordinating both hands in one activity is a problem. For example, when I attempt to chop wood with two hands on the ax handle, I consistently hit left of target. Using only my right hand, however, I am able to strike where I aim.

Recently, a tremor has developed in my right hand and arm. Before it was only slight, now it is more pronounced and nearly constant.

Selective memory loss continues and cannot be restored. I have lost recollection, for example, of an entire trip involving driving to another city, visiting relatives, and attending a wedding. I remember things that happened before and after but not during that trip. Looking at the wedding pictures and even talking to relatives about it does not jog my memory.

Temporary paralysis and extreme fatigue are the biggest problems. And the two are closely connected: When one happens the other follows immediately.

Very little exertion, even walking through a grocery store, is, for me, a major expenditure of energy. I must use care to pace myself and gets lots of rest daily or be afflicted with, first, fatigue and, then, paralysis of my left side.

The nerves in my left eye are sensitive to light, and too much light causes paralysis on my left side followed by great fatigue. Walking a short distance in the sunshine is possible for me only if I wear both sunglasses and a cap.

Even driving is possible only if I am careful to screen light striking my left eye. Once, I forgot to wear sunglasses during a drive. Within a few minutes, fatigue and paralysis began, but promptly went away after I donned sunglasses.

Scar tissue on my auditory nerves allows even sound to cause paralysis and fatigue. Background music in restaurants and shopping centers can be a problem. Consequently, I must carefully avoid noisy places and wear earplugs when I can't. Once again, just getting away from the source of the noise makes the paralysis and fatigue recede.

Because my nervous system is also heat sensitive, I avoid warm surroundings both indoors and outside and rely greatly on air conditioning, both in buildings and in automobiles.

By resting several hours everyday after lunch, by carefully pacing my daily activity, and by avoiding moderate and strong light, heat, and sound, I cope with my susceptibility to paralysis and fatigue.

All aspects of my environment need to be carefully monitored, since the physical impact on my nervous system is cumulative. By this I mean that small amounts of light, heat, and sound, combined with exertion, can add up to exacerbate my MS and drain off my reserves of energy.

For me, adjusting to MS means a drastic curtailment in former activity. Dances, concerts, and restaurants are avoided altogether. Occasionally, I go shopping, but I am always prepared to return home if my MS becomes exacerbated. Outdoor activity in warm weather is not possible, and outside my residence I carry dark glasses and earplugs.

Since my energy level is very unpredictable, I am always flexible in my plans. I do not hesitate to cancel some activity if I begin to feel ill. After all, there is always another day. But if there is something special I really want to do, I am careful to rest up beforehand.

By knowing about my situation, I hope readers will better understand why Richard Queen can have a serious medical condition, requiring hospitalization, and still appear well and able-bodied at a press conference.

He has real physical problems, but they come and go, and may worsen with time. Nevertheless, with care and self-discipline, Queen, like many other MS patients, can reduce the discomfort and the limitations of the disease.

In doing this, the MS patient also strengthens his mental outlook. This is important, since radical and unexpected changes in health, interrupted plans, and uncertainty about accomplishing any given task help cause anxiety and depression.

MS is a complex disease, difficult to diagnosis, not easy to live with. But, for those of us with MS, that is the first thing that must be learned—how to live. By wisely making the necessary changes in our lifestyle, we can still be productive and complete people.

—Glen Zimmer

Mr. Zimmer is a free-lance writer.

Carderock Naval Research Center: A Special Summer Intern Program

Summer has finally wound down, and, before you know it, several weeks into the semester will have passed. We'll all soon be preparing for exams.

By now, if you're like me, you're probably wishing you were back at your summer job. I'm sure many of the summer interns who were employed this past summer at the Naval Research and Development Center in Carderock, Maryland, are wishing that they were.

Unlike many of the other summer intern programs in the DC area, the one in Carderock is unique in that it specifically employs disabled students. The program has been in effect for several years.

"We advertise the summer position openings at disabled student organizations in several colleges around the country," stated Paul Meyer, program manager and technical recruiter for the Center. "And that is why we have a lot of disabled students applying for the internships."

Some of the students who worked at Carderock this summer were residents of the immediate area, but most of them came from other parts of the country, with the Midwest being highly represented. Besides being from different locales, the students also varied in their ages and educational experience. Most of the students were undergraduates, but there were several graduate students in the program, as well as a few high school students.

The majority of the students were hearing impaired; there were a few visually impaired students; and some students used wheelchairs.

"We really have the cream of the crop here each year," Meyer stated. "I talked with about 200 students interested in the internships this year, and over 100 students applied. We then chose the interns from those applicants.

"The goal of the program, though, is not in numbers," Meyer continued. "Rather, our goal is to gainfully employ the students. We try to place the students in jobs which are related to their field of study and will benefit them."

The program, which began in 1974, has grown from the employment of its first mildly disabled student to its present number of 40. The reason for the success of the program has been due in part to the enthusiastic support of the technical recruiter, civilian personnel officer, and the commander of this Navy Center.

Along with the increase in the student intern populaion, there has also been an increase in services for the students over the years. Besides being equipped with MCM's and TTY's for the deaf students, the Center hired a full-time interpreter for the first time this summer. Sign language courses were also offered to the interns and to the full-time employees during working hours.

For the visually impaired students, the Center purchased video enlargers and a braille teletype. There were no permanent readers employed at the facility this summer, but co-workers usually offered their assistance when needed.

Accessibility has also improved at the site over the past few years, although from my observations when I visited there, more needs to be done to accommodate people in wheelchairs.

"Accessibility is still pretty poor," commented Bill Shepardson, a 24-year-old senior at the University of Missouri who uses a wheelchair. "Some buildings are not accessible at all, and others need more modifications."

The policy of this Naval facility is to make accessible the buildings in which full-time disabled personnel are employed. "It's kind of a 'Catch 22' situation," Shepardson continued. "They don't make any modifications until after they have hired the disabled person. Why should a disabled person want to come to work here if it's not already accessible?"

Shepardson, and almost all of the other summer interns, lived for the duration of their internships at Gallaudet College. "It's the cheapest way to live!" stated Molly Deegan, a 23-year-old blind student who is studying law at Cleveland State University.

Arrangements regarding accommodations were made with Gallaudet prior to the students' arrival. All of the students with whom I talked spoke highly of their stay at the College.

The students were housed in the College's newest dorm, and had the College's food services program offered to them. Having already tasted the delicacies of institutional food, most of the students opted to cook their own meals in the kitchenettes located on each floor of the dormitory. Although many of the disabled students living there were not deaf, most made an effort to learn sign language.

Each morning the students gathered bright and early, formed their car pools, and reported to the Carderock installation at six in the morning. There they worked at their respective job sites until quitting time at three in the afternoon.

Lisa Gale, a 22-year-old deaf student from St. Louis Community College, shared some of her experiences while working on a special project to develop a brochure about affirmative action for hiring disabled people.

"People often asked me how I could communicate with Molly, (another intern), because sometimes it is difficult for blind people and deaf people to communicate. Molly is learning sign language, and I learned to read her lips pretty well. So I usually had no problem understanding her.

"If my speech wasn't comprehendible, I would fingerspell what I wanted to say into her hand. Of course, if I had a lot to say, I looked for someone who could interpret for us."

As far as communicating with the other interns and staff members, Gale said she didn't usually have any difficulties. "If they couldn't understand what I was saying, or if I couldn't lipread them, we usually wrote down what we wanted to say.

"I did have a problem when I wanted to make a phone call to someone. We had a TTY in the office, but if I wanted to make a call to another office, they didn't always have a TTY. Then I had to rely on someone else to interpret the call."

Since this Naval installation is concerned with researching and gathering information about ships, many of the interns were math or science majors and were employed in this capacity. Some worked with computers and in other computer-related fields. Several of the students worked in clerical positions.

"My big disappointment," stated Shepardson, "was that I was told over the phone that I'd be doing one thing, but when I arrived here, I was given a totally different assignment."

"I enjoyed the summer here," Gale commented. "It has given me the opportunity to work with people who have different types of handicaps."

Molly Deegan described her summer job as being "a good experience. Working in this group and doing the paper on affirmative action together has been good for me. Usually I have a tendancy to work alone, so this project has encouraged me to work with others."

Deegan is interested in focusing on environmental or civil law once out of school. "I became interested in law," Deegan said, "because it didn't seem to me that disabled people were getting what they should—I didn't know if this was because of people's attitudes or legislation."

Jean Purdue, who has been supervising disabled students for two years now, commented, "The students have problems like any other employee—they have the same pet peeves and they goof off, just like everybody else."

Purdue just recently began taking sign language classes at the facility. "Communication is still sometimes a problem with a few deaf students," the supervisor stated.

"There were times I gave people assignments to do, and I thought I was understood. But, later I found out I wasn't. This summer I put a lot of information in writing and I started to use my signing skills, too.

"We also had a problem in keeping the deaf students who were hired as secretaries from getting bored. Most secretaries have a lot of phone interruptions which break up their day a little bit. But, the deaf secretary doesn't have these interruptions, and most of the day is spent typing. So we tried to find useful work for them to do that would help break the monotony of typing."

Not only did the students enjoy and learn from their internships, but many staff members have grown since the program started.

"When I first began supervising students," explained one supervisor, "a student came whose arms were small and deformed and who relied on a wheelchair. Upon seeing him, the first thing I did was pity him. As the summer passed, and my attitudes changed, I watched him not only excel in his work, but in everything he did.

"I finally asked him at the end of the summer, 'Is there anything you can't do?' He looked at me with a smile on his face and said,'Yeah, there is one thing I can't do—give birth!' I won't forget him. He was special."

For those of us who look back at our summer internships as we struggle to complete our college requirements, there is much to remember. As Jean Purdue, who supervised the interns at Carderock pointed out, we all had our pet peeves, but also an office worker or two that became a special friend.

For the interns at Carderock, there was a special challenge—not only were they learning new skills, but they were also teaching those they worked with how much they could do. But, hopefully for them, as for me, as summer turns to autumn, the pet peeves, hard work, and special challenges become vague memories.

What is remembered are the people we worked with, especially the one or two out of all the others that became our friends.

—Ellen Blanchard

Ms. Blanchard was a President's Committee summer intern from Gallaudet College.

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the Chairman's Column

CHANGING TIMES...
The Communications staff of the President's Committee has been doing some adding and subtracting in the last few months. Lynn Park and Muriel Horton-Strassler have moved on to exciting new challenges. Additions to the Communications staff are Robert Gorski, new associate editor of "Disabled USA" and Lucy Skinner, new program assistant for the magazine.

Robert, a disabled consumer advocate, comes to us from the Institute for Information Studies in Falls Church, Virginia, where he worked as a research assistant. Prior to that, he worked in service programming and community resources at the Westside Community for Independent Living in Los Angeles, California.

Lucy is not new to the Committee. She transferred to Communications from State Relations. As program assistant to the magazine, she is in complete charge of the mailing list (everyone please note!) and assists in all aspects of the magazine's production.

We wish those who have moved on a fond *adieu*, and we welcome our new staff members.

MAGAZINE FEATURES...
"Amicus," the bimonthly journal of the National Center for Law and the Handicapped, devoted the entire issue of Vol. 5, No. 1 to international topics. This was done in recognition of 1981 as the International Year of Disabled Persons.

The issue examines laws and policies of other countries, including the areas of education, employment, transportation, and accessibility. Also included is an examination of the purpose and effectiveness of United Nations declarations.

Individual copies of this "Amicus" issue are $2.00 ($2.75 outside the US). Contact: Jean Postlewaite, Publications Coordinator, "Amicus," University of Notre Dame, P.O. Box 477, Notre Dame, Indiana 46556. (219) 283-4536.

DISABLED EDUCATORS...
The American Association of Colleges for Teacher Education (AACTE) wants you—if you are a disabled educator. The AACTE is trying to locate people with disabilities who are in the education profession so they can participate in a project called "Section 504 and Teacher Education."

The project will attempt to identify and collect information about disabled people who are teachers, administrators, education students, and employees or officials in education-related agencies. They also want to identify people who have been restricted from training or employment in education because of their disability. Information collected will be used to identify barriers obstructing participation of handicapped people in education.

To participate in this project, write: Section 504 and Teacher Education Project, AACTE, Suite 610, One Dupont Circle, N.W., Washington, DC 20036

OOPS...OOPS...OOPS!
In the Chairman's Column of Vol. 3, No. 7, we gave information about a "Job Hunter's Kit" available from the American Association of University Women. In quoting the cost ($10.00), we neglected to note that all orders must be prepaid. Sorry we forgot.

NEW SMITHSONIAN TDD NUMBERS... The Smithsonian Institution recently changed all of its telephone numbers. The new Smithsonian TDD numbers for the deaf will be: The Special Education Program—357-1696. Visitor Information—357-1729. Museum of History and Technology Education Department—357-1563.

PUBLICATIONS NOW AVAILABLE...A directory of Agencies Serving the Deaf-Blind is now available for purchase. The directory was compiled from a list of agencies reporting services to the deaf-blind.

Orders may be sent to Ms. Gertrude Queen, Librarian, Helen Keller National Center, 111 Middle Neck Road, Sands Point, NY 11050. Cost: $5.00

. . .A new directory contains information on agencies which provide recreation and leisure programs and services in the Los Angeles area. Directory includes private, non-profit, and municipal programs.

This publication was written for people in the Los Angeles area, but it also contains information of value to other areas.

This information includes: 1) Local, State, national, and international organizations concerned with the handicapped—especially those concerned with accessibility, sports, travel, and leisure activities. 2) General resource information on all aspects of recreation. 3) Leisure activities for persons with physically disabilities—includes information on arts and crafts, assistive devices, accessibility, sports, travel, and camping.

This Directory can also serve as a model for creating similar directories in other geographic areas.

Cost: $7.95 each ($1.00 discount to handicapped persons; California residents add 6% sales tax.) Mailing fee: $1.00. Send check or money order to Mickey A. Christianson, M.T.R.S., 11066 Gonsalves Place, Cerritos, CA 90701.

. . ."Inside Out" is a new booklet on attitudes toward people with epilepsy, and other hidden disabilities. *Includes:* Myths and facts about hidden disabilities, examples of attitudinal barriers and possible solutions, and what can be done about existing attitudes. Also includes a list of organizations representing hidden disabilities.

Copies are available from the Regional Rehabilitation Research Institute on Attitudinal, Legal and Leisure Barriers, RRRI Publications, 1828 L St., N.W., Suite 704, Washington, DC 20036. Make checks or money orders payable to George Washington University. Price: $.50 per copy. (No discount for bulk orders.)

SCHOLARSHIP OFFERED... Physically disabled persons between 15 and 35 years old who are interested in improving their education and who meet certain requirements, have an opportunity to compete for a $1,500 cash scholarship.

Criteria for the Student Aid Award, given every two years by the Venture Club of the Americas, is based on financial need and the capacity to benefit from further education. The deadline for applying is February 1, 1982.

For an application and the address of the Venture Club nearest to you, contact Monica Gizzi, Program Secretary, Soroptimist International of the Americas, 1616 Walnut Street, Suite 700, Philadelphia, PA 19103. The President's Committee also has a limited number of applications available.

CALIFORNIA HERE WE COME... United Airlines in conjunction with Pinetree Tours, Inc. is offering a special tour package to California. The package provides special handling for wheelchair travelers and those with other limitations. The tour is offered on a "go-any-day" basis. Most importantly, the tour guarantees that the hotels, attractions, and facilities will be accessible to handicapped people.

Specially equipped vehicles accommodate travelers with mobility limitations—motor coaches and vans are equipped with power lifts and tie downs for wheelchairs. Drivers of the Pinetree vehicles are specially trained and first-aid certified.

The tour package includes both San Francisco and Los Angeles, and special group rates are offered. For more information, contact your local United Airlines office.

WORK INCENTIVE BILL... Three years of lobbying and planning paid off for backers of the "Work Incentive Bill for the Handicapped" when Minnesota Governor Al Quie signed the bill. The new bill allows individuals on Medical Assistance or Minnesota Supplemental Aid to work and retain half their medical benefits.

The bill will provide a greater incentive for people with disabilities to find meaningful employment. (Taken from "Courage News," June, 1980, Courage Center, Golden Valley, MN.)

Harold Russell

THE PRESIDENT'S COMMITTEE
ON EMPLOYMENT OF
THE HANDICAPPED
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